Mom's Journey Through Senior Living:

A Family's Story

WRITTEN BY INDUSTRY INSIDER -
MANDY HAMPTON, THE RIDGE SENIOR LIVING CEO

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Welcome

Dear Friend,

As I write, it's been 16 months since my mother moved into a senior living community. I would say some days are as peaceful as a day at the lake with a cold beverage. Others are neck deep in the swamp breathing from a straw.

This guidebook shares my personal journey in stories, insights, and some recommendations as a daughter of a resident through the unique lens of being a senior living expert. I've done my best to break these insights into categories. The timelines might have overlapped a bit depending on the situation. I might not have all the answers, but I have some, and I hope they will help — or you can have a good laugh at my expense.

Either way, I wish you and your family the best on this journey.

With heartfelt support,
Mandy Hampton
The Ridge Senior Living CEO

The Physical Move

Once mom decided it was time to move into the community, it was “game on.” I’d been waiting patiently for 18 months for this decision, and I had every intention of capitalizing on it. Logistically, it was daunting. Nothing had really been downsized or changed in the seven years since my dad suddenly passed away. To make things even more fun, she decided to move to California from Montana to be near my brother Eric (more about him later). So, we needed to get her packed into six large suitcases. Why six, I can’t recall, but that was the edict, and off I went.

Packing

First, clothes. She was going from having seasonal clothing with warm winter jackets and boots to essentially summer year-round with some jackets. We spent days evaluating every single piece of clothing. I had to leave the room when she insisted on packing 40 pairs of socks. We got it down to 20 with a promise to buy more when we got to California. Then came the decorations and sentimental items that she wanted to take. Everything else was boxed up and put in her garage. What she put into the suitcases ranged from rocks to ornamental hunting knives to pictures. After failed negotiations, I just let her fill up the suitcases with whatever she wanted. I may have removed some things (for safety) without her knowing. At the very last minute she decided that she wanted her bedspread. It meant something to her, so we made room. We had towers of boxes in the house all labeled and ready to be put in the garage. I even put signs on them (with her permission) “don’t unpack — for the garage.” When I came back, they were indeed unpacked and the suitcases were a mess. After the third round of this I decided that the boxes were going in the garage. Out of sight, out of mind, right? Sure, until the garage was open and then we see her out there, again insisting she needed her stand mixer in her new apartment. Needless to say, my intent to move quickly backfired big time. She needed more time to process this change. I could have used that time to enjoy being with her. Looking back I should have. Mom spent three weeks rummaging through those bags and waiting by the front door to leave.

Pro Tips

- Plan early: What are the most important things that your loved ones should be surrounded with, and will they fit? Compromises will be made, and feelings will get hurt, so get clear on what matters to them and you. We video-recorded my mom over several hours walking us through the house and her property so she could tell stories about each item and what she wanted done with it.

- Do NOT pack family heirlooms or anything that could get lost. If you want to inherit your family quilt don't take it with you.

- Clothes should be based on how much space you have. I would recommend 2-4 weeks of seasonal outfits if you are limited. If not, pack seasonal clothing in totes or compression bags that can be easily stored under beds or offsite. Laundry service will be specific to the community. Usually, you can expect 2 loads per week unless there are additional needs. Some communities have laundry rooms for residents or their family members to use, as well.

- Command Hooks will be your friend. You'll be surprised how many things you'll want to hang.

- Be prepared for a lot of pre-move-in coordination. Every community and state has different requirements. Licensed communities normally require assessments, current physicals, and orders for every single medication (including OTCs). It makes it even harder when you come from out of state.

- Ask upfront exactly how the move will happen. Do they have dollies, or flatbed carts to move heavy things? Is there a service elevator? When do we get the keys? Are there times when we cannot move things?

- Get measurements for the apartment up front so you know what will and won't fit.

- Ask the maintenance team which walls can support heavy items — such as a TV. You also don't want to drill holes into pipes behind walls.

Settling In

We ordered furniture in advance, and the community was gracious to store it for us until her apartment was ready. Since I was 1,500 miles away, I was doing my best to get the small stuff ordered and delivered to save my brother the extra trips. I was also dealing with medication coordination, a new doctor, physicals, TB tests, and all the paperwork the community needed signed. Had it not been electronic, it would have been a paper stack 4 inches thick. I read every word; granted I am an expert, so I was more curious than most on the specifics, but I would encourage you to do the same. It's as important to know what is NOT included as what is. I suggest you get all the move-in documents in advance, so you aren't scrambling at the last minute. Missed expectations can cause resentment, and knowing up front allows time to plan for what's to come.

Eric decided to take a week to get everything set up and then moved her in on a Monday. Some communities don't allow weekend move-ins so ask in advance. Also, we wanted to be sure that the whole management team was there in case something was needed. The first few weeks were great. She made friends, she participated in activities and really enjoyed the food. Family checked on her almost every day and took her out for family activities. This was looking like an A+ move-in success! All our problems were solved, hurray!

Pro Tips

- Get a copy of the activity calendar and menu in advance and start planning what the first few days will be like.
- Make sure they're comfortable navigating the community without you. Have them take you to areas such as the dining room, nurses office, front desk etc. Transitions are hard and it will take time to acclimate. Some residents will take days if not weeks to settle into a new routine. Expect some confusion, and if they don't bounce back quickly, please talk to the community and ask for a care plan meeting.
- Send the community's address to friends and family early or right after moving in. Getting letters and postcards makes an enormous difference.
- Consider a scheduled delivery of commonly needed supplies. You could even use companies like Insta Cart for urgent or as-needed items.
- Rugs are not usually a great idea unless they have non-slip backing, especially in the bathroom.
- Read the community handbook or the contract on anything that is not allowed such as candles, space heaters, or even certain cleaning chemicals.
- Get a mattress cover. I repeat, get a mattress cover!
- Get a broom, Swiffer, or a small vacuum between cleaning days. You will also need small trash cans.
- Bring or purchase hobby items that they enjoy and can work on in their apartment or bring to shared areas.
- Get furniture that can be wiped down (couch, chair).
- Label clothing or important items for residents with memory impairment.

Reality Check

My mom has an early onset Alzheimer's diagnosis and a long history of mental health issues. She was diagnosed with Alzheimer's at 66, which makes her 20 years younger than most of the residents in the community. Physically, she's in great shape and is easily mistaken for the daughter of a resident. This led to jealousy among other female residents when Mom could dance without assistance, and the men were really into that. She had two marriage proposals in that first month! And while the jealousy was minimal, it was enough to send her into a spiral. Over the next few months, she spent significant amounts of time crying in the nurse's office and forgetting how to get back to her apartment. She also went shopping on a normal outing and filled her cart with $650 worth of items she did not need. When she got to the checkout counter, she had no idea how to pay nor could she remember her PIN number. She was embarrassed, and now we needed to be concerned about what she could buy on her own.

We brought in every possible medical expert at our disposal to stabilize her. This included onsite nurses, doctors, psychiatric, physical therapy, and continued support from her therapist in Montana. We were all doing our best to untangle dementia and depression and determine how to treat it. (By the way, depression is common for people with dementia and, in my experience, can accelerate a person's decline without interventions.)[1] The medical team recommended serious medications which had their own list of side effects. I was staunchly opposed but relented after much discussion with my uncle and brother. She was suffering, and we had no other option but to try. And as it turned out, the medications were effective. But in January (three months after her move-in) my brother got a call from the Assisted Living Director. She said Mom was wandering the hall with her bra outside her shirt, and it was time to go to Memory Care. This was not a discussion; it was a firm boundary: Mom needed more help, and she needed it now. My vision of what I thought my mom's senior living experience would be imploded, and I went into swings between panic, grief and my CEO-get-things-done mode.

[1] Source: Alzheimer's Association

Pro Tips

- When your loved one has access to a credit or debit card, consider limiting purchase amounts or receiving notifications to your phone/email to ease your concern. You could also leave a pre-paid card in their wallet and refill it as needed.

- Most residents move in with multiple health conditions and need coordinated care.[2] Meet with the appropriate department directors and find out the best way to communicate needs and changes. Outside providers often call on the resident and notify the community about what they did or what was discussed. This could be a group email or text thread or a meeting with all parties involved. Care plan meetings are common and can be done in person, over the phone or via video chat. I recommend that you involve all the key players so everyone hears the same thing.

- When your loved one in assisted living has memory impairments, be prepared for an eventual transition. Most communities will set up care plan meetings to discuss their concerns or observations in advance. However, abrupt changes might be warranted, especially if there are safety concerns.

- Senior living communities are no different from other settings. You'll find amazing humans and a token table of mean girls. Ask the team members (they will know) who your loved one would be a good fit with.

- Pick your battles. Unless you've worked in senior living, you can't fathom the amount of physical, emotional, psychological, and spiritual toll this job requires to be successful. No one's perfect, including your loved one.

[2] Source: ScienceDirect; Patterns of chronic co-morbid medical conditions in older residents of U.S. nursing homes: Differences between the sexes and across the agespan

What I wish I had taken more seriously before her diagnosis:

It's no secret our family has a history of Alzheimer's. Some families have histories of cancer, heart disease or stroke. The truth is, the longer we live, the less we can do. That's part of the human condition, and it becomes easy to overlook warning signs when you see the worst outcomes on the news or social media. These were not dramatic red flags, just small shifts that added up. And we should have taken a harder look at these earlier on.

- **Mail and Taxes.** She was great about checking the mail. But sorting and doing something with the bills was sporadic and then stopped. We found her 2023 taxes hidden behind a picture of Jesus. Thank goodness that many of her bills were on autopay.
- **Shopping.** She hoarded staples, such as flour, sugar and oats like we were preparing for the end of time. However, she did not know how to use them and would forget what she already had on hand when shopping.
- **Cooking.** The refrigerator filled with snack food and nothing that required actual cooking. Yogurt, premade salads, cheese sticks, and crackers were staples. She would come to my house most nights for proper meals. At one point she wasn't even able to heat up the leftovers I sent home with her.
- **Cleaning.** When she was traveling we began to deep clean, and I was beyond upset about what we found: moldy spoiled food in the pantry, dust on the fan blades inches thick, and dozens of bottles of medications and vitamins — and no one knew what they were for. I called for help with this.
- **Gardening and Lawn Care.** Her house is on 26 acres, which is a lot for anyone. She had a beautiful vegetable garden that she tended every summer. But over the course of two summers, we went from harvesting more than we could eat to a haven of weeds and overgrown raspberry vines.
- **Driving.** At first, there was occasional forgetfulness on where she parked. Then came the full-on panic attacks when she was lost in the parking lot. She missed exits and forgot turns. And there were fender-benders — which were invariably someone else's fault or due to terrible road conditions.
- **Money.** I'm glad Mom didn't obsess over this. She would and still does ask where it all is. We assure her all is well, and she's happy with that. In other families, I know valuable may be hidden or hoarded. Sometimes there are accusations of theft when things are misplaced.

Transition to Memory Care

The first decision we faced was financial. The community had one memory care apartment available, and it was designed to be shared by two people. We could take the whole apartment, or she could get a roommate. Despite how social my mom is, there was no way a roommate was happening. We opted to rent the entire apartment, pay a significant price for it, and put her on the waitlist for a private apartment. The upside was the apartment was larger, with a similar layout to her assisted living apartment, so 99% of her things would fit. We decided to have her spend most of her days in memory support so she could start meeting people and get accustomed to the routine. We also told her she could still eat with her friends in assisted living (that lasted about two weeks) to make this as easy as possible. Eric showed her the apartment, and she seemed on board. On moving day Eric took Mom for a full day and night so the community could get her things moved. It all looked great except she knew immediately her painting supplies and personal care items were gone. She didn't care about the body wash, but it was war over the paints. The director immediately replaced them with non-toxic paints, but she knew those were not hers and she accused the staff of theft. I showed the community her watercolors were nontoxic, and they were brought back — much to to Mom's relief. I was also frantically buying all new non-toxic personal care items online for delivery. Some states have very strict laws about what can and cannot be kept in memory care apartments.

Pro Tips

- When your loved one is transitioning into memory care, do a sweep of what will not be allowed. It could be cleaning supplies, steak knives, scissors, crochet needles, or anything that could be harmful. Remove those ahead of the move.
- Ask the community who is doing the move. In our case, we paid the community to do it. Some might waive the fee; others might ask you to bring in a moving company.
- If the transition is safety related, the community might ask for 1:1 care until they have been moved. This added expense is very high, so coordination is critical.
- Ask the community if they have transitional daytime programming for those who are about ready to make the move. If so, it's an effective way for residents to start acclimating and for you to meet staff and understand what the unfamiliar environment will be like.

Transfer Trauma

Moving your mom three times in 90 days is not a good idea. I would give it zero stars. The first week or two we held our breath hoping this was the best thing for her. Eric was there daily, and the staff worked to keep her engaged in meaningful activities that gave her purpose. Mom has always been a caretaker, so she quickly found other residents she could help. After those initial couple of weeks, Mom started seeing a cat outside her apartment window. We told her it was probably a neighborhood cat and not to worry. But her observations escalated to a story of the cat being in danger because the staff was going to kill it. Then she claimed a man was hiding in her closet, and he was going to hurt children. She took markers and drew on her clothes, claiming the staff did it. When she said a staff member kicked her, the ensuing investigation revealed that Mom was hallucinating. One day she refused all her medications and was on the verge of being sent to an in-patient geriatric psych hospital. We immediately had more meetings with the medical team, and adjustments were made to her medications. Our fear was she was going to be incoherent from the side effects, but we had no choice. She was living in terror. But the meds worked, and once everything settled down, she apologized to the staff member she accused of kicking her, and it ended with hugs and grace on both ends. That apology was critical for the staff members to hear. Being accused of something like that almost made them quit, which would have hurt the community in the end. Abuse can happen, but in my experience it is rare. Residents often lash out at staff for a number of reasons and it causes burnout.[3] This was especially hard for me since I spend much of my professional day advocating for staff retention. The irony is not lost on me.

[3] Source: BMJ Open; Burnout among care workers in long-term care institutions: a systematic review and meta-analysis protocol

Pro Tips

- Make moves with intention, especially for those with memory loss.
- The #1 reason staff come to work is for the residents. The #1 reason they leave is mistreatment from residents and the family members.
- Weigh the pros and cons of medications. Tough decisions will need to be made, especially toward the end of life.

Family Dynamics

Every family has its story. We're all human, after all, and we get it wrong sometimes. There may be secrets, emotional cut-offs or unresolved conflicts. Too often, I've had to watch as an out-of-state daughter or son flies in, disrupts the process for family, resident and community, and then leaves again. The result is painful mayhem for the care staff, as they can no longer be certain who the family's decision-maker is. And it's the loved one, the resident, who suffers. The lesson is plain: Even when you can't get everyone in the family aligned, you can still protect the relationship with the community by having one clear decision maker.

I'm the oldest of five siblings in my family, and we're far from perfect. Today, my siblings and I are in different places, and our family dynamics are as tricky as any. But Mom picked me and Eric, the middle child, to assume powers of attorney when she could no longer make decisions independently. We've accepted the responsibility, determined to do right by her. As for her move to the senior living community, Eric and I have agreed to serve as the point of contact for the community, keeping the community from being involved in or affected by anything going on in our family.

Caring for someone in senior living is a team effort. Don't make the community the enemy. Most of the time, communicating clearly and managing expectations resolves troublesome situations. It's also important to be clear about what end-of-life care will look like now and in the future. Due to age and other medical conditions, many residents in assisted living and memory care pass sooner than you expect. As an example, if your loved one fell and fractured a hip required surgery and extensive therapy. What would you do based on their wishes? Those conversations are ripe for long term resentments if clear plans are not laid out upfront respecting your loved ones' wishes.

Hospitalizations & Falls

I want to be frank about the likelihood of falls while living in the community. I suggest that you and your families talk openly about this and what they want to happen if it does. More likely than not, a fall will happen, especially if your loved one suffers from dementia, Parkinsons, MS or a multitude of other diseases. These falls can occur anywhere, anytime — including at home. They may result in scratches, bruises, bone breaks or, in the worst cases, injuries that lead to death. If your loved one has frequent falls, there should be care plans in place to address the underlying issue. Is there a rug that should be removed? Do they refuse to use their walker or wheelchair? Did they fall out of bed? Did their legs give out? Care plans are effective when staff and residents are compliant. As active and physically strong as my mom currently is, I still expect she's going to fall. Dementia will take her ability to walk and any sense of safety awareness.

If a major injury happens (or is suspected), the community will likely call 911. It will then be up to EMS, the resident, and the POA to determine if transport is needed. There are always extenuating circumstances, but that's the general rule. When a resident is sent to the hospital via ambulance, the community should be calling the first responsible party in their file. And that person needs to be prepared to meet them at the hospital or to delegate someone else. It would be rare for someone from the community to accompany a resident to the hospital. EMS should be provided with a copy of the resident's "face sheet," which has all the basic information, a copy of their medications list, and any other critical information (such as a DNR/POLST) from the community. The family member or designee will need to relay family history and, either with or on behalf of the resident, decide what care will be provided. For example, if there's a hip fracture, and all parties need to agree to surgery. Post-surgical recovery will possibly require physical therapy in a skilled nursing setting for several weeks. Family member or designees will need to discuss this with the hospital's case manager and the community representative to determine the next steps in recovery.

Real Life Scenario

My mom was recently hospitalized for nearly a week. Of course, it happened when my brother was on vacation. She was becoming progressively more agitated, and no amount of redirection or medication was helping. The memory care director phoned us and said she was calling 911 for a psych hold. That meant that the police and EMS were on their way. I silently prayed my mom would not become physical with the police and end up restrained or even worse, tased (I've had this happen before in communities). Luckily, she was very sweet, and the staff had to convince EMS she needed to be transported. Once she arrived, we needed to mobilize family members to be with her because there was no way she could communicate what was going on to medical staff. While that was happening, I was on the phone with the nurses, giving her medical history and making sure they knew the seriousness of the situation since she was very calm and happy for them. Fortunately, the hospital took me seriously and admitted her. We then spent several days with multiple psychiatrists, nurses, doctors, case managers, and 24x7 sitters coordinating the next steps. Once she was stable and ready for discharge, the memory care director came to the hospital to see Mom and ensure she was ready to come back. I had made sure that the director was getting regular updates, so she and the staff knew what was happening, preparing her and the staff to change Mom's care plan and update her medications. The lesson in this story? Once your loved one is out of the community, it's your responsibility to assume coordination of care and communication across multiple channels. It's a lot of moving parts, and I want you to be ready if you are faced with a similar situation.

When Things Go Sideways

One day, Mom was more agitated than normal, and redirection wasn't effective. Within a few days she was planning her big escape with several residents joining her. She would push on the doors waiting for them to unlock. That progressed to her shoving staff out of the way when she was at the door. She finally managed her big break after holding the door for 30 seconds, knowing it would unlock (fire code), and made it to the opposite side of the community before she was caught and returned. Over the course of a week, she punched a staff member in the back of the head, punched and kicked the memory care director who was trying to give her medications, and threw medications at another staff member.

This caused absolute chaos within the community and our family. We've been on multiple calls with care staff, her doctor, the psychiatrist, and the memory care director. We're unbelievably grateful that every single person we've interacted with has been quick to respond and intent on helping her. There was no blame other than the disease. The question is: What do we think is causing the change, and is there anything we can do about it? Antibiotics were ordered before any testing was done, based on symptoms. Onsite visits (multiple) from the doctor and psychiatrist resulted in other medication changes. Care plan meetings were held, and of course the family group's text messaging was in full effect. My brother was there multiple times each day, apologizing to staff and redirecting and attempting to reason with mom. Nothing worked, and I spent many days praying they weren't going to kick her out.

Like anything it's a wait-and-see situation. Will the antibiotics get her to baseline, or does she need more anxiety meds? What is the benefit to her and the community with medications that could cause more sedation? How much is it too much? Does upping the medications mean she's going to forget us even sooner? All these questions and concerns are legitimate and must be carefully considered for her and all of those around her.

What we do know is that she is suffering, and it is our responsibility to lean into what her written and verbal wishes have been long before this point. This has been hard for us to accept. We might have made different choices for our own lives, but that's not for us to project onto her. This part of her journey has been the most difficult for her and us. I would not wish this pain and confusion on anyone.

Pro Tips

- Be clear with any family members about your loved one's long-term wishes. Wills, trusts, POA's, DNR's should be created prior to moving in and on file at the community.
- Assign one point of contact for the community to communicate with.
- Set up a text or email thread to provide everyone with updates as needed.
- Allow input but remember that someone must make tough decisions.
- If in-patient skilled nursing care is necessary, determine where that will be and for how long. The community still requires rent to be paid during this time. Check to see if your contract waives care fees while they are receiving care in a higher-level setting such as skilled nursing.
- If a situation escalates quickly and outside of the norm, get an order for a UTI test.

Technology

Technology used correctly can be a blessing. But sometimes, it's a curse. Mom has her iPhone. On good days she can make a call and sometimes even answer one, including video chats. Text messages are questionable, at best. On bad days she leaves it uncharged in the freezer and blames anyone but herself. We've removed all apps that aren't essential. But her phone continues to be a lifeline for her to connect with us. Nevertheless, when you get 36 missed calls and 12 voicemails during the night, you seriously question what connection is. She has also called 911 multiple times, wanting to talk.

We know we're on borrowed time, and these issues will fade away. It's devastating to think this essential part of her life will just not be used. What are we going to do to appease our guilt? Most communities (including hers) have platforms you can opt for to notify you when your loved one attends activities, send you pictures and keep you informed of events. They're also used for community-wide notices or emergencies. I highly recommend you opt in. There are also devices you can put in the apartments to video chat, but my mom kept unplugging hers. I personally discourage nanny cams, and, in some places, they're not allowed, due to privacy concerns. If you feel the need to manage your loved one's care by spying or monitoring those cameras 24x7, there are bigger issues to discuss.

Pro Tips

- Determine the capacity for types of technology. Be ready to pivot and simplify.
- Sign up for whatever communication tools the community offers.
- iPhones have new settings under accessibility that are specifically designed for older adults. Use them.
- Some TV remote services, such as Jubilee™, can help control the TV when the remote goes missing or when operating the remote becomes too complicated.
- Air Tags are essential. My mom's remote and phone frequently go missing, and the staff and my brother Eric spend hours hunting for them.

Sidenote

On expectations:

There's no doubt I would care for my mom differently, but that doesn't mean how she's being cared for is wrong or bad. On my first two visits, I spent valuable time tidying up the messes my mom made in her apartment instead of just being with her. On my next visit, I refrained. Since it wasn't bothering her, I let it go. My need for order and tidiness is not hers. Granted, if I saw something unhygienic, it would be addressed. But I can let the brown spots on the bananas be ok. Every single day the staff encourages her and meets her where she is. I have such respect for people who can be screamed at one minute and then sit with that person with kindness and lack of judgement. Pick your battles; you have no idea what happened ten minutes before you arrived.

Caregiver Burnout

Moving someone into senior living will solve some problems and create others. There's no magic solution for an aging loved one or those who care for them.

When it comes to a loved one with dementia, an important question to consider is this: How do you maximize the time that remains with them? What are the priorities and expectations? I think the most powerful question you could pose to your loved one is "what do you want this experience to be like for you and me?" Is it a lot of family time filled with love and laughter? If so, it makes your priorities clear and many other concerns can fade away. I know that's what my mom wants. The last thing she would want is to be a burden while her children fight about what we think she wants and then our guilt dictating her experience. The best thing we can do is honor what she wants — even if it's not what we want.

Caregiver (including you) burnout happens for myriad reasons, but usually it's based on the lack of acceptance of the situation or the false belief that you have control.[4] As a self-diagnosed control freak, this has been the hardest lesson of all for me. Mom's disease is in control, and the sooner I can accept it, the more at peace we'll both be. Acceptance doesn't mean defeat. If anything, it proves how incredibly courageous and resilient you are. The people who embrace this rarely do it alone. They're surrounded with supporters who give them room to process and grieve. Be selfish about who joins you in this journey; many will not have the capacity, and that just adds more pain to a painful experience. This is time for quality, deep connections. If you struggle with this, join a support group. You aren't alone.

I also want to add that once your loved one makes this transition into senior living, you get to go back to your role as a child, spouse, or friend, and it takes time to get readjusted. All the hours I spent filling medications, letting her in the house when she locked herself out in the middle of the night, or making sure her food was stocked — suddenly those responsibilities just vanished. I'm still on the phone coordinating care with my brother, but my calls with Mom are about her being my mom. For that, I'm infinitely grateful. I do worry about my brother and all that he's taken on. We check in almost daily to so I can be assured he has the support he needs — even if it's just a listening ear or a funny meme.

[4] Source: BMJ Open; Burnout among care workers in long-term care institutions: a systematic review and meta-analysis protocol

Pro Tips

- Ask your loved one the hard question: What do you want and expect for you and me while you're here? Honor it.
- Pick your people. Some will step up and others will run for the hills. You can't do this alone.
- Support groups or therapists are highly recommended. You aren't born knowing how to care for someone at the end of their life.

End of Life

This section is hard to write and hard to read. If you aren't ready, that's ok. Come back when you are.

My mom's disease has no cure, and it has stolen at least 10 years if not 20 of her life. Whether your loved one has Alzheimer's, cancer, CHF, COPD or any other terrible condition, they're on borrowed time. It's important that you understand what the end of life may look like. Does your loved one want CPR, being hooked up to feeding tubes and intubated? I watched my father go through this when he was 61, and it was horrific for him and my family. I'll never fully recover from seeing him attached to about every machine the hospital had available. Did we fulfill his wishes? I believe so, but we were guessing. We certainly didn't have any plans for this in writing. My mom has made different choices, and I'm grateful we have a roadmap that we can follow. The community is obliged to follow those legal documents too.

Hospice

The first thing to know is that hospice is a service, not necessarily a place. There are physical settings for it, but most residents receive these services in the familiar comfort of their apartments at the community. The other good thing is that hospice is 100% covered by insurance.[5] Finally, something that our premiums pay for!

The general rule is that someone who has fewer than six months to live can qualify for services. The resident must be evaluated and accepted, since insurance is paying for it. Once that is squared away you may be pleasantly surprised to see how many services are provided. Onsite nurses, bath aids, equipment, medications, counselors and clergy, if you want.

I'm a huge proponent and have seen it extend the life of many people. If your loved one lives past the six months, they will be re-evaluated to determine if they continue to qualify for services. Sometimes, people "graduate" and no longer require hospice services. On the other hand, I knew a resident who was in hospice for 4.5 years. Each person is different, and hospice caregivers will be there to walk you through it.

[5] Source: Medicare.gov

Pro Tips

- DNRs, Wills and Trusts are critical for end-of-life success. Have the hard conversations and paperwork completed before you're sitting in an ICU deciding in the middle of the night if you keep fighting or not.
- Hospice is a gift for residents and families. Make use of it on your team.
- It's likely your loved one will have falls, wounds, infections, or other issues along the way. Be clear on how your loved one wants to address those. Some can be easily fixed with a bandage or round of antibiotics. Others may have no cure.
- Know which mortuary you intend to use when the time comes. Put the number in your phone. This will be mandatory info for the hospice company and community.

The Good Stuff

Now that we got the hard stuff out of the way, let's end with the whole point of senior living: connection and purpose. Every single person needs these two things to survive and thrive. Senior living offers that by the truckload. Communities, by design, create connections through shared meals, activities, and events. We have a community where a group of residents researches stocks. I really want an invite to that one! Activities look different based on abilities, but that doesn't mean they're less important. My mom still goes out to restaurants, bowling, and dances. She even attended a car show wearing a lavender loofa sponge proudly pinned to her dress as a corsage. Did we stop her? No, she thought it was a flower, so it was a flower. The best part was that no one shamed her. She is accepted for who she is, and who doesn't want that?

You can expect that your loved one will make friends and become close to them. They will often eat and socialize together, visit each other's homes, and sometimes even argue. Imagine 100-plus grandparents living under one roof. It's ripe for entertaining interactions, and the staff sometimes call it unscripted reality TV.

I highly encourage you to spend these precious months — or years, if you're lucky — documenting their memories. I've made it a habit to record my mom's calls so I can remember her voice when she's gone. Video record them telling stories or just having a normal day. If they aren't comfortable being on video, the voice notes feature on your phone is great to keep recording in the background. There are plenty of prompts you can download online to help spark conversations. The number of family secrets that get revealed in communities is wild!

Pro Tips

- Encourage participation in activities and events. If they don't like the offerings, create your own.
- Be prepared to see people at various stages of life. My mom came out of her apartment this week to encounter a male resident completely undressed. Instead of being horrified and blaming staff, we just understand that he was confused and meant no harm.
- Residents in memory support may wander into your loved one's apartment. We were searching for my mom's phone and found 20 pairs of glasses in her dresser! I think four of them were hers.
- Most communities accept and encourage furry friends. Make sure you ask about the rules for pets if that's needed.
- Be ready to change your plans, including holidays. If they need to leave sooner or come later, be flexible. A good two hours together is better than six terrible hours of being upset. Communities love to throw parties, so consider having celebrations there.

In Closing

I'm 21 years into working in senior living. So many times I've sat bedside during a person's passing, honoring the memories of family and friends with smiles and tears. This is a business of humans caring for humans, and it's both messy and magical.

At the end of this chapter, I include helpful documents, checklists, and resources you might need. Many of these I've used professionally, and they seem to work for most people. Every community is different, but I would say most of these resources should be applicable to you.

This process has taken an enormous toll on our entire family. On the one hand, I know Mom's safe and her basic needs are being met. There's comfort in that. On the other hand, the guilt, anger, and sadness of our reality is crushing. Every day I swing between asking for more time and then begging for mercy to take this pain from her quietly in the night.

I've had to evaluate how I work through these issues in my professional life. I hope that I'm more forgiving and understanding than I was when I first started. Getting complaint calls for service failures still stings, but I also now understand the other side of where all this stems from.

Alzheimer's may eventually take my mom from this earth, but I refuse to let it define her worth to herself or to our family.

I promise to love you, Mom, even when you forget my name.

Thank you for reading. I wish you all the best during this journey we call life.

Mandy

Pro Tip Cheat Sheet

I've included a comprehensive list of all the pro tips scattered throughout this book. Highlight your favorites, cross out those that you don't feel apply to your unique situation, and come back to it when you find yourself looking for answers.

The Physical Move

- Plan early: What are the most important things that your loved ones should be surrounded with, and will they fit? Compromises will be made, and feelings will get hurt, so get clear on what matters to them and you. We video-recorded my mom over several hours walking us through the house and her property so she could tell stories about each item and what she wanted done with it.
- Do NOT pack family heirlooms or anything that could get lost. If you want to inherit your family quilt don't take it with you.
- Clothes should be based on how much space you have. I would recommend 2-4 weeks of seasonal outfits if you are limited. If not, pack seasonal clothing in totes or compression bags that can be easily stored under beds or offsite. Laundry service will be specific to the community. Usually, you can expect 2 loads per week unless there are additional needs. Some communities have laundry rooms for residents or their family members to use, as well.
- Command Hooks will be your friend. You'll be surprised how many things you'll want to hang.
- Be prepared for a lot of pre-move-in coordination. Every community and state has different requirements. Licensed communities normally require assessments, current physicals, and orders for every single medication (including OTCs). It makes it even harder when you come from out of state.
- Ask upfront exactly how the move will happen. Do they have dollies, or flatbed carts to move heavy things? Is there a service elevator? When do we get the keys? Are there times when we cannot move things?
- Get measurements for the apartment up front so you know what will and won't fit.
- Ask the maintenance team which walls can support heavy items — such as a TV. You also don't want to drill holes into pipes behind walls.

Settling In

- Get a copy of the activity calendar and menu in advance and start planning what the first few days will be like.

Pro Tip Cheat Sheet Continued

- Make sure they're comfortable navigating the community without you. Have them take you to areas such as the dining room, nurses office, front desk etc. Transitions are hard and it will take time to acclimate. Some residents will take days if not weeks to settle into a new routine. Expect some confusion, and if they don't bounce back quickly, please talk to the community and ask for a care plan meeting. Send the community's address to friends and family early or right after moving in. Getting letters and postcards makes an enormous difference.
- Consider a scheduled delivery of commonly needed supplies. You could even use companies like Insta Cart for urgent or as-needed items.
- Rugs are not usually a great idea unless they have non-slip backing, especially in the bathroom.
- Read the community handbook or the contract on anything that is not allowed such as candles, space heaters, or even certain cleaning chemicals.
- Get a mattress cover. I repeat, get a mattress cover!
- Get a broom, Swiffer, or a small vacuum between cleaning days. You will also need small trash cans.
- Bring or purchase hobby items that they enjoy and can work on in their apartment or bring to shared areas.
- Get furniture that can be wiped down (couch, chair).
- Label clothing or important items for residents with memory impairment.

Reality Check

- When your loved one has access to a credit or debit card, consider limiting purchase amounts or receiving notifications to your phone/email to ease your concern. You could also leave a pre-paid card in their wallet and refill it as needed.
- Most residents move in with multiple health conditions and need coordinated care. Meet with the appropriate department directors and find out the best way to communicate needs and changes. Outside providers often call on the resident and notify the community about what they did or what was discussed. This could be a group email or text thread or a meeting with all parties involved. Care plan meetings are common and can be done in person, over the phone or via video chat. I recommend that you involve all the key players so everyone hears the same thing.
- When your loved one in assisted living has memory impairments, be prepared for an eventual transition. Most communities will set up care plan meetings to discuss their concerns or observations in advance. However, abrupt changes might be warranted, especially if there are safety concerns.
- Senior living communities are no different from other settings. You'll find amazing humans and a token table of mean girls. Ask the team members (they will know) who your loved one would be a good fit with.
- Pick your battles. Unless you've worked in senior living, you can't fathom the amount of physical, emotional, psychological, and spiritual toll this job requires to be successful. No one's perfect, including your loved one.

Pro Tip Cheat Sheet Continued

Transition to Memory Care

- When your loved one is transitioning into memory care, do a sweep of what will not be allowed. It could be cleaning supplies, steak knives, scissors, crochet needles, or anything that could be harmful. Remove those ahead of the move.
- Ask the community who is doing the move. In our case, we paid the community to do it. Some might waive the fee; others might ask you to bring in a moving company.
- If the transition is safety related, the community might ask for 1:1 care until they have been moved. This added expense is very high, so coordination is critical.
- Ask the community if they have transitional daytime programming for those who are about ready to make the move. If so, it's an effective way for residents to start acclimating and for you to meet staff and understand what the unfamiliar environment will be like.

Transfer Trauma

- Make moves with intention, especially for those with memory loss.
- The #1 reason staff come to work is for the residents. The #1 reason they leave is mistreatment from residents and the family members.
- Weigh the pros and cons of medications. Tough decisions will need to be made, especially toward the end of life.

When Things Go Sideways

- Be clear with any family members about your loved one's long-term wishes. Wills, trusts, POA's, DNR's should be created prior to moving in and on file at the community.
- Assign one point of contact for the community to communicate with.
- Set up a text or email thread to provide everyone with updates as needed.
- Allow input but remember that someone must make tough decisions.
- If in-patient skilled nursing care is necessary, determine where that will be and for how long. The community still requires rent to be paid during this time. Check to see if your contract waives care fees while they are receiving care in a higher-level setting such as skilled nursing.

Technology

- Determine the capacity for types of technology. Be ready to pivot and simplify.
- Sign up for whatever communication tools the community offers.
- iPhones have new settings under accessibility that are specifically designed for older adults. Use them.
- Some TV remote services, such as Jubilee™, can help control the TV when the remote goes missing or when operating the remote becomes too complicated.
- Air Tags are essential. My mom's remote and phone frequently go missing, and the staff and my brother Eric spend hours hunting for them.

Pro Tip Cheat Sheet Continued

Caregiver Burnout

- Ask your loved one the hard question: What do you want and expect for you and me while you're here? Honor it.
- Pick your people. Some will step up and others will run for the hills. You can't do this alone.
- Support groups or therapists are highly recommended. You aren't born knowing how to care for someone at the end of their life.

End of Life

- DNRs, Wills and Trusts are critical for end-of-life success. Have the hard conversations and paperwork completed before you're sitting in an ICU deciding in the middle of the night if you keep fighting or not.
- Hospice is a gift for residents and families. Make use of it on your team.
- It's likely your loved one will have falls, wounds, infections, or other issues along the way. Be clear on how your loved one wants to address those. Some can be easily fixed with a bandage or round of antibiotics. Others may have no cure.
- Know which mortuary you intend to use when the time comes. Put the number in your phone. This will be mandatory info for the hospice company and community.

The Good Stuff

- Encourage participation in activities and events. If they don't like the offerings, create your own.
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Move-In Checklist

Moving to assisted living or memory care presents challenges beyond the complications any other move can bring. This checklist provides a little structure and focus as you work through emotions and the often-tight deadlines you face.

Remember to bring ...

Hygiene Products

- [ ] Shampoo
- [ ] Soap
- [ ] Lotion
- [ ] Toothbrush, toothpaste and denture-cleaning supplies (if needed)
- [ ] Deodorant
- [ ] Electric shaver
- [ ] Perfume or aftershave
- [ ] Incontinence supplies
- [ ] Comb and brush
- [ ] Lens cleaning supplies

Linens

- [ ] Plastic mattress protector and mattress cover
- [ ] Bed sheets (at least 2 sets)
- [ ] Towels and wash cloths (at least 2 sets)

Don't bring ...

Area rugs
Bed rails
Inedible flowers or plants
Cellphones
Valuables
Sharp objects
Cleaning supplies
Pets without prior approval

Remember to ...

- ✓ Label everything
- ✓ Give signed, dated prescriptions and all medications to staff
- ✓ Verify daily dining and snack schedules
- ✓ Verify laundry schedule
- ✓ Notify friends and relatives of change of contact information

Resources

Learning and Support

Alzheimer's Association: www.alz.org
Government Alzheimer's: Information www.alzheimers.gov
Dementia Training: www.teepasnow.com
AARP: www.aarp.org
Hospice Foundation of America: www.hospicefoundation.org
The Five Wishes: www.fivewishes.org

Senior Living Industry Info

Argentum: www.argentum.org
LeadingAge: www.leadingage.org

Senior Living Industry Context

The Senior Living Insider Podcast: Listen on YouTube, Spotify or Apple Podcasts

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