

“What I Wish I’d Known”

28 Nuggets of Wisdom from Family Caregivers



All too often, it just happens: A parent or spouse falls or gets sick and a “routine” hospital visit becomes far more serious – a diagnosis that could require specialized care, a move from the family home, and care from professionals and/or family caregivers. Providing that care can be tremendously expensive and stressful. Yet due to our reluctance to talk about death and dying – much less plan for it – and a perfect storm of demographic trends, society has little help to offer those struggling with these issues. Each day, 10,000 Boomers turn 65; Alzheimer’s and other forms of dementia are on the rise; financial costs are skyrocketing ... and caregivers & family can suffer from emotional, physical, mental, relationship & financial damage during this “story with no happy ending.”

If you’re a caregiver now (or want to plan ahead, which is ideal), wisdom from someone who has been through a similar experience can make all the difference. In the two years we spent developing our expertise and creating our new workshop, “Seasons of Care: Caregiving for Elders in Your Family,” we spoke to many people who generously and courageously shared what they learned caring for their parents. We compiled their advice and hope their wisdom will resonate, perhaps making your own experience a bit easier.

The “SEASONS OF CARE” workshop is free and open to the public (we encourage you to bring family/friends, too). We’re holding our next session on November 13, from 11:30am-1:30pm (lunch included.) To learn more, visit <http://hello.joynadvisors.com/caregiver-workshop>.

Finally, if you find these tips valuable, we hope you’ll share them with family and friends. Caregiving is one of the most important issues our society isn’t talking about, and we need to change that mentality – quickly.

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1. **Hire in-home caregivers a month before you think you need them.** By the time you decide you're ready, you've reached the end of your rope, and it takes time to work you into their schedule. If possible, hire caregivers early enough that your loved one is able to tell you if the caregiver treats them well.
2. **Call 911 first - be embarrassed later.** Emergency responders are not there to judge you - they're there to help you.
3. If your parent is living in a big house or way out in the country, **encourage them to move sooner rather than later** so they have time to adapt to their new home and make new friends before they become sick or frail.
4. **Palliative care is not either/or.** You can see a palliative care doctor at the same time as your loved one is undergoing life-saving treatment. Even if you think your loved one might be months away from death, ask to speak to a palliative care doctor. We waited too long and I wish we had done so earlier.
5. **There's value in a "therapeutic lie."** For example, instead of saying, "Give me your keys, Mom, you can't drive anymore," you can say, "Mom, the doctor said you can't drive while you're taking this medication." (Make sure everyone is on board to avoid unhappy contradictions.) We called my mom's caregiver her "driver," which she would accept, not her "caregiver," which she would not.
6. **Get power of attorney** for your parents' bank and investment accounts early. None of my parent's banks or brokerage houses would take the power of attorney my dad's attorney had drafted. They insisted he sign their forms instead, which put a big strain on him and me.

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7. If you’re the primary caregiver, you’re probably going to be spending a lot of your own money. It’s hard (both emotionally and logistically) to get paid back later. **Save all receipts** in a big plastic envelope that you keep in the car and write notes directly on them—chances are you won’t remember later.
8. **Stress and grief impair thinking**—no matter how well you think you’re doing. I still haven’t found my mom’s handwritten address book that I distinctly remember taking from her house the day she died so I could let people know.
9. **There are two parts to caregiving:** the sprint (driving over to mom’s house to figure out why the smoke alarm is going off) and the marathon (day-to-day caregiving with no set end date). You have to be prepared for both and you can’t do everything like it’s a sprint. Take care of yourself, too.
10. **I should have had some difficult conversations with my parents and family earlier.** I needed help figuring out what to say and how to say it. I could have saved a lot of heartache if I had better conflict resolution skills.
11. **You need to understand your parents’ financial resources.** Ask a financial advisor to help you figure out how much money you’re likely to need, especially if you’re going to be paying for all or part of your parent’s caregiving.
12. **Caregivers often wind up being the one dealing with their parents’ estate, too.** It would have been great to have a list of who mom wanted to give what things to instead of hearing, “But Mom promised that to me.”

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13. **Make sure your caregivers are properly vetted**, and if you can’t always be there, listen to what others report about how they treated your parents.
14. My mom had a long-term care insurance policy, but the caregivers we hired didn’t have the “right” license so the insurance company never reimbursed us for any of her caregiving. **Check with the insurer before you hire a caregiver** and make sure you understand when it kicks in.
15. Once you have power of attorney, **ask your team (financial advisor, attorney, and accountant) if you should take care of anything NOW** before your loved one loses capacity to make decisions or dies. I learned I could have fixed the beneficiary designation on my mom’s IRA and paid less in estate taxes but I didn’t know about it.
16. **Have a family meeting earlier** to discuss basic mission and specific responsibilities - before you’re exhausted and everyone is emotional and stressed out.
17. What I wanted most while caring for my mom was a “thought partner,” someone who would help me think about all the things I hadn’t considered. I felt like I was reinventing the wheel. **Find someone to help you think so you don’t have regrets.**
18. Remember that once you tell your bank that your loved one has died, they are required to put a hold on the account. **You’ll need some way to pay the mortgage and bills until you establish and fund an estate account.** (And our bank didn’t allow online banking from estate accounts to autopay bills, either!)

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19. **I wish I’d hired a caregiver earlier.** I spent a lot of time driving my mom to doctor’s appointments, monitoring her medications, etc. It was exhausting and not fulfilling. Hiring a caregiver allowed me to spend time just enjoying being with my mom—to be, not just do. That time was a gift to both of us.
20. **Hiring caregivers means trusting others with your loved one and with their things, and that’s hard.** You’ll never have complete peace of mind, but you can take jewelry, heirlooms, and other valuables out of the house before you bring the caregivers in.
21. Taking care of first my dad, then my mom, made me realize that **I needed to get my own affairs in order** so I wouldn’t be a similar burden to my own children.
22. Not everyone is ready to talk about mom or dad dying. **Be compassionate to those who might feel differently than you right now.** Eventually, your parents will be gone and you don’t want to rupture your relationships with your brothers and sisters.
23. Caregiving can reverse family roles. Sometimes you’ll be your parent’s child and sometimes you’ll feel like you’re the responsible adult taking care of them—causing confusion, tension, and frustration for all. **Find someone who can help you navigate difficult conversations or difficult people, or talk with a therapist.** After a few sessions, my therapist told me, “I think you now have the tools you need. You just need some place you can be sad about what’s happening.” Her words made me feel so validated and supported.

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24. Your parent might become ornery or difficult (or has been long before getting old/sick. **You have to decide what you’re willing to put up with and what you’re not, and get others in place where needed.** At the end of the day, I realized that caring for my aging parent was less about my mom and more about what kind of daughter I wanted to be. When I decided I wanted to do the best I could be, I could let go of more of the things that annoyed me.
25. **When a parent is first diagnosed with dementia or Alzheimer’s, there’s a window of opportunity to get things done,** to learn what their wishes are, to set things in motion, and to have those meaningful conversations. Take advantage of that time, even if starting those conversations is uncomfortable.
26. Caregivers have knowledge and experience you don’t. **They can share tips about making home safer (like “take the knobs off the gas stove”) that you might not think about.** My mom didn’t want to be touched, but she let the caregiver massage her skin with lotion - something she’d never let me do for her.
27. **Caregiving, especially long term, can strain your marriage.** With everything you’re feeling and all the demands on your attention, it’s easy to think your spouse will understand and accept what’s happening. But you and your spouse need each other before, during and after this stressful time, so don’t sacrifice this relationship.
28. **Forgive yourself.** Caregiving is hard work. You’re going to wish you’d done some things differently. Hiring helpers, making mistakes, or grieving for your own loss doesn’t mean you don’t love your parents—it means you’re human.

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If you know others who can benefit from this advice, we encourage you to share this document!

If you have advice/tips to add, please do so via the comments section (if online) or by email to tamara@joynadvisors.com.

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The workshop is free and you’re welcome to bring family and friends. Please make sure they register so the caterers can feed everyone!