Cost of Caring for Aging Parents

[Editor's Note: The following guest post was submitted by Margaret Curtis, MD, a pediatrician who writes about career and finance for women at [ADoctorsWorth.com]() and frequents the [WCI forum]() as "Crockett's River". Dr. Curtis was the primary decision maker and financial manager for both of her aging parents for about six years total – four of those years she was caring for both at the same time! We have no financial relationship.]

I was the decision-maker for both my parents at the end of their lives. They had very different end-of-life trajectories: one was a best-case scenario, one a cautionary tale. I learned a great deal about navigating the tricky financial, legal and familial waters of caring for elderly relatives, and I hope my experiences might help some of you in your personal and professional lives. If nothing else, I hope reading this inspires you to [sharpen up your own estate planning]().

Cost of Caring for Aging Parents – Best Case Scenario

My mother retired in her sixties with a substantial nest egg, after a life of hard work and thrift. She was later diagnosed with Parkinson's but lived independently for many years doing what she enjoyed most. When her symptoms started to interfere with her daily living, she moved into an assisted living. This brings me to the first lesson learned:

1) Put Care in Place Early

We all know patients who lived at home alone "as long as possible", and it often doesn't end well. There are real financial implications here too: friends of ours recently moved into a retirement community that includes independent living as well as skilled nursing and memory care. They moved while they still qualified for independent living (ie while they could both still pass a mini-mental status exam), so they locked in the lowest daily rate (adjusted for inflation) for the rest of their lives. No matter how much care they need, they will only pay the "independent living" rate. Given that memory care can be many multiples the price of assisted or independent living, this could mean the difference between outliving their money and leaving something for the grandkids. Not all senior care facilities offer this (incredible) deal, but moving when you are still independent gives you many more choices for location and price, because there are always more assisted living beds than skilled nursing facility (SNF) beds available (just ask any medicine intern who has tried to find a rehab bed for a patient on a Friday).

My mother's living facility was affiliated with the hospital where my husband was an attending. Later, when we moved for my training, she moved with us. We were able to see her regularly and talk with her caregivers. My kids got to know her. This is lesson #2:

2) Keep Them Close

I often hear people say, "I won't move close to the kids because I don't want to be a burden." Trust me, you will be more of a burden living across the country than across town. This is more practical than financial advice (unless you include the expenses of traveling to visit elderly parents, which becomes more frequent over time), but it will directly affect everyone's quality of life. You will also be able to draw on your professional community to help your parents if they live nearby. I don't mean anything unethical, such as preferential treatment but just the fact that we were on a first-name basis with her PCP made us all feel better.

When my mother first moved into assisted living she transferred her assets into a local bank that has a "wealth management" division. Because her assets totaled over $1 million (seriously, hard work and thrift), she qualified for a private banker who cut checks for her expenses and monitored her asset allocation over time. That is lesson #3:

3) Get Professional Financial Help

Even if you are a die-hard financial DIYer, I strongly recommend getting at least some help with finances. First, because it frees you up to do other things, like be a doctor. Second, because it insulates you from what can be ugly wrangling over money. For example, we soon found out that a relative had regularly been asking my mother for money. Mom was never able to say no to this person, but Margie the Private Banker sure could. That conversation probably saved my mother more than she paid in fees for assets under management. If your parents' assets don't qualify for your own Margie, you might want use a CPA or lawyer for account management (below I discuss some other professional services that might be helpful). If you do all the accounting yourself you have to be meticulous in record-keeping to avoid even the appearance of impropriety.

Dr. Margaret Curtis, MD

With careful planning, my mother was able to live out her life in comfort, without worrying about her finances. We were able to enjoy her last years with a minimum of stress, for which I will always be grateful.

Cost of Caring for Elderly Parents – Cautionary Tale

Now, the Cautionary Tale. My father was diagnosed with Alzheimer's in a scenario that will be familiar to EM docs: he walked into an ED of a major medical center and announced that he was there for his surgery. Needless to say, he wasn't scheduled for surgery. He was admitted for evaluation and disposition. I heard about this a few days later when a hospital administrator called to say he couldn't be discharged home. She told me that if I or my siblings couldn't arrange suitable housing he would be reported to the state as an "elder at risk". She couldn't tell me anything about the results of his evaluation due to HIPPA regulations. Now, this is where our system defies common sense: I needed to take over his affairs and find housing for him and to do that I needed some kind of legal standing. To get legal standing, I needed documentation that he was no longer competent. To get documentation, I needed legal standing. After a few days of phone calls and 'round-the-mulberry bush conversations, a hospital social worker took pity on me and said, "This is ridiculous. I'm going to tell you that your father has dementia, probably Alzheimer's." I thanked him profusely, hung up the phone and called my lawyer to discuss options.

Cautionary Tale Lesson #1: You Will Need a Team

No amount of medical training will prepare you for wandering in this particular wilderness. I recommend your team includes:

1) A Professional Guardian

This may be the most valuable member of the team, and one I learned about late. The National Guardian Association describes the process by which individuals can act as fiduciary caretakers and overseers of both person and estate. The NGA also keeps a database of individuals and agencies who do this work. Although I acted as my father's guardian, I believe hiring a professional who has both legal, financial and elder-care expertise would be invaluable. The best professional will have many services (including a CPA, attorney, and home health care expert) under one roof, or have close ties to these services.

2) A Lawyer

This lawyer doesn't need to specialize in elder or estate law but should be able to refer you to a specialist if need be. We used a lawyer who had helped us with a real estate closing. He guided me through the process of obtaining guardianship and later held the bond for my father (see below).

3) A CPA

Depending on how simple or complicated your parents' estate is, you may be able to manage tax issues yourself but for the sake of transparency and avoiding costly mistakes I recommend at least consulting a CPA at the outset.

4) Local Elder Care Agencies

These elder care agencies can vary from government agencies to local United Way offices. They generally don't take an active role in managing an elder's affairs but can offer help with finding resources. Just google "elder care in (location)".

5) Do Not Expect Your Team to Include Family Members

I realize I'm straying away from financial advice again, but if you are going to get through this with family ties intact you need to have realistic expectations. Old family roles reassert themselves and conflicting interests make decision-making difficult. (A relative who lives in a different country once told me I should really be bringing my mother more fresh fruit. At the time I had a job, 3 kids under age 7 and 2 incapacitated parents. Do not be that relative.)

Legal Guardianship

Filing for Legal Guardianship

I filed for legal guardianship, which was fairly easy. My lawyer filed the paperwork (although you can also do it yourself with a google search), then my lawyer and I met a judge at the county courthouse to present supporting evidence. I submitted the results of his neuropsych evaluation and explained how I had gone to his home to move him and found a fridge full of rotten food, etc. I had to get a bond, which is essentially an insurance policy that would replace his assets in case I, as guardian, absconded with them. Because his assets only totaled about $200,000, the bond cost about $50, renewed annually.

Guardianship vs Power of Attorney

Guardianship gave me the capacity to make all legal, financial and medical decisions for my father. It is worth laying out the differences between guardian and power of attorney (POA): POA is designated by an individual to make legal and financial decisions for that individual, should she become incapacitated. POA does not automatically include health care decisions such as do not resuscitate (DNR) or do not intubate

(DNI); for that, a durable power of attorney (DPOA) for healthcare (or healthcare proxy) needs to be designated. A guardian is appointed by the court to make all decision, including medical. An individual who has lost capacity can't name a POA (which is why I applied for guardianship). *Guardianship trumps POA.* I encountered actual hospital social workers who did not understand this distinction.

Guardian Reimbursement

You are entitled to be reimbursed from your parents' funds for the time you spend on guardianship activities. I chose not to do this, because he had so little money left, but if you go this route you should absolutely have a CPA or professional determine the going rate for guardianship and cut the check. Again, avoid even the appearance of impropriety.

Banking

I established a bank account for the benefit of (FBO) my father, with myself as the sole check-writer. I kept the bulk of his money in a low-cost money market fund and periodically transferred cash into his checking account for his few expenses. His Social Security check was deposited directly into his account, and the bill from his memory care came out automatically.

Be Prepared to Straighten out Financial Messes

When I started going through his finances, I found my father owed several credit card companies and hadn't filed tax returns in several years. I don't mean he had no tax liability; I mean he hadn't even filed. I figured the credit card companies would find me on their own, but I didn't want to keep the IRS waiting so I contacted his local IRS office (easy to find online). The agents were very understanding and gave us enough time to get all the forms filed. I paid our CPA (from my father's account) to recreate his returns as best we could using bank statements and social security records. Luckily he didn't owe any back taxes so as soon as we filed his case was closed.

I met with a bankruptcy lawyer who offered a free initial consultation, to see if he should go into bankruptcy to protect his assets from creditors. She explained that he really didn't have enough assets to protect at that point – he didn't even own a car – and that filing would cost more than it was worth. She recommended I settle with the credit card companies to accept partial payment of his debts, which is what I did. Your situation may differ if your relative has substantial assets, and it may be worth consulting an attorney if a large debt is involved.

Running Out of Money for Care

My father's finances put him in a difficult situation; he was too wealthy to qualify for Medicaid but would only be able to pay for private memory care for about 3.5 years. Fortunately for him, my mother had purchased Long-Term Care for him years ago and paid all the premiums. This covered about 30% of his expenses for 3 years, so gave him about another year of private pay memory care. (I would add "buy LTC insurance" as lesson #2, but that kind of affordable policy really isn't available anymore. If you have it already, count yourself lucky and do not miss a payment). We would have to do the dreaded Medicaid spend-down; pay for his care out of pocket until he met Medicaid limits, then move him into a Medicaid or veteran's memory care facility.

Now at this point you may be thinking, "Only one of my parents needs skilled nursing care! Why don't they just get divorced (in name only), so we don't have to spend down all their funds?" Nope. Judges see right through this kind of shenanigan. If a couple gets divorced, there is a waiting period before either can get state assistance.

I started looking for a Medicaid memory care facility almost as soon as my father was settled in his first, private-pay facility. I knew such facilities were in short supply. In fact, I couldn't find even one that would take his name on a waiting list. I finally found a private, non-profit elder care services agency that was able to help. I found this agency online as I described above, and had I known about them I would have enlisted their help far earlier. I paid them an hourly rate to help with his case, and they were able to find a nearby veteran's home that would put him on the list. When the home moved glacially slowly in processing his paperwork, the agency dogged them and even suggested I write to our state senator for help. (I did, and it worked).

You will notice that I paid for my father's care largely out of his funds, and we did not offer (or even seriously consider), paying for his care out of our pockets when he ran out of money. The cost would have been literally half our take-home pay at that point. The decision of whether, and how much, to support your parents is entirely personal. Miss Bonnie MD does a nice summary of issues to consider here: https://missbonniemd.com/financially-ill-prepared-parents/ and there have been threads on this topic in the WCI forum. Again, a good CPA might be helpful in deciding how best to proceed if you want to help support dependent parents.

Conclusion: Save A LOT For Retirement!

My father lived comfortably and quite happily in his memory care unit until he died. He did not have to move, thankfully, and died with about 4 months living expenses left in his bank account. So this brings me to the final lesson, and I know I am preaching to the choir here, but:

> *Save for retirement. Save a lot. Old age is expensive, and dementia is even more so. You may be saving for a 40-foot cruiser (and for your sake, I hope you get it), but I am saving so my kids never have to put me in a public nursing home.*

I hope this information is helpful, although I also hope none of you ever find yourselves dealing with a Cautionary Tale. If you do, or even if you have questions about what I have written, please feel free to contact me. If I don't know the answer I may be able to point you to someone who does. If you never have direct care or oversight of elderly loved ones, remember to thank those who do. And I wish you and yours all the best.

Have you needed to care for aging parents? What advice can you add? Comment below and share your experience with others.