

Motley Fool's *Rule Your Retirement* Newsletter

How to Cope as a Caregiver

Robert Brokamp, CFP

September 07, 2018

Brokamp: According to AARP, more than 40 million Americans provide some level of care to an adult friend or relative. Caregivers, on average, are 49 years old, which means they also have jobs and children to tend to, but actually nearly one in 10 are 75 or older taking care, likely, of their spouse.

On average caregivers have been providing this service for four years, but 24% of them have been doing it for five years or longer, and caregiving can range from just help with shopping, cleaning, and transportation all the way to caring for someone who is bedridden. The typical caregiver spends more than 20 hours a week providing...

Southwick: Wow!

Brokamp: ...for his or her loved one. So being a caregiver can be emotionally, physically, and financially challenging. Here to help us with advice on how to best manage these challenges is Amy Goyer, AARP's family and caregiving expert, and the author of *Juggling Life, Work, and Caregiving*. Hello, Amy.

Amy Goyer: Hi, thank you for having me.

Brokamp: Sure, welcome to *Motley Fool Answers*. Let's start with your story. How did you become an expert in caregiving?

Goyer: Well, I've worked in the field of aging for about 35 years. I started my career out as a music therapist. I worked in adult day care centers and nursing homes. Then I worked for the Ohio Department of Aging. Then for AARP full time. Then about nine years ago I went on my own as a consultant.

And at the same time (pretty much that whole time), I was also caregiving; first for my grandparents as a long-distance caregiver. I was in Ohio. They were in Indiana. And then my mom had a stroke when she was only 63.

Southwick: Oh!

Goyer: Then my dad became her primary caregiver. They had moved to Arizona -- I was still in Ohio -- and my dad was an only child. For him, caregiving for his parents in South Bend, Indiana was tricky at a long distance, so I did a lot of the driving over, in-person stuff, and he managed the finances and those kinds of things from a distance. That evolved over time.

Then my mom had this stroke, so I had another role of being backup for Daddy. Later on, he had a hip replacement, so I went out and spent a month. I telecommuted and took care of Mom, and did the dogs, and cooking, and all that good stuff. Sometimes those things were temporary kinds of things. Then over time my parents started needing more and more help. My dad developed Alzheimer's disease. My grandmother had, had it too, so we were always worried that would happen. And then on top of that, my older sister had Cushing's disease, which is a rare disease that's a tumor in your pituitary gland that makes your whole body go crazy.

So I was her power of attorney. She had a good local network. She lived over in Maryland. About nine years ago, I moved from here in Alexandria to Arizona. I kept my place, here, because my work is based in DC, but I was in Arizona most of the time and came back and forth every month. Kind of a crazy life existence, there. My sick parents moved into a senior community and then three years later moved back in the house with me when they both needed 24-hour care.

When you think of the cost -- and many people don't realize this -- they moved into a senior community that was independent living, but they still had meals, there are services and it's expensive. And then when you start needing continuous care (somebody to really help you), then you're adding on and adding on, and there's just not enough money. There wasn't enough money for them both to be in assisted living. Even then, it

wouldn't have worked, because my dad was at that point where he couldn't be alone for five minutes. And I had to work, so I couldn't be there constantly.

By moving them in with me, we saved some money. We consolidated. I hired a live-in caregiver five days a week to help and then I did the weekends by myself. Over time things changed. My mom passed away a year later and my sister, who had been living in Ohio (one of my other sisters), moved to Arizona to help with Dad. She brought her two sons. They lived with us for a year and then the house next door came open for rent. So they lived next door...

Brokamp: Wow!

Goyer: And it's been amazing, because as I mentioned to you, my dad just passed away about a month ago. It's been a really rough time since then, but I'm starting to get to that point where I can look back and evaluate. I've been so lucky to have had some family support like that. My dad got to a point where we couldn't convince him to get out of the chair. He could do it, physically, but he didn't understand. Didn't want to. It took two people to convince him and help him get up. We had to call my nephew to come run over from next door. When you think of the cost of having two people all day, it just was prohibitive. There was no way to do that.

You get very creative with how you do things. I feel really good about the fact that we had Daddy at home. He was walking up until the last two days of his life. He was up, and dressed, and had a shower. He had quality of life. He had lots of music -- Lawrence Welk, thank you -- and so I feel really good about that.

And now, since we talk about finances a lot, I'm in the position where it's really been very financially crippling for me. Keeping up two places, going back and forth, being self-employed, so no benefits. Insurance is expensive. All of those things. And also just getting my dad everything that he needed. We did some creative things with Alzheimer's and I think that's part of why he did so well.

He was 94 years old when he died. He had acupuncture, and he had massage once a week, and we had reiki. We kept him exercising. I had someone who came and worked out with him in the water. Those things are all what made the biggest difference in his quality of life and his health, and our ability to care for him, but they add costs, and so I absorbed all that.

Southwick: You have really been on the front lines of experience with this.

Goyer: Totally. And that's one of the things we talked about. Caretakers don't recognize themselves as caregivers. You talk about you're taking someone to the grocery store. Well, I took my grandmother to the grocery store. She never drove. And I had a caregiving role, then. I didn't think of myself as a caregiver.

I was just a granddaughter doing what you do, and then as time goes forward I had a very different role with my other grandparents, who needed a lot of help. Then I had a different role with my mom. And even that role, with her, changed over time to a point where I provided complete personal care her every need (toileting, bathing, grooming, everything). And the same for my dad. So we have to realize that you're a caregiver if you're calling your mom every day to check on her. And you're a caregiver if they're living with you and you're providing personal care. And there's a lot in between.

Brokamp: I'm sure a lot of people hearing your story are thinking of their own parents, their own grandparents, or maybe even their spouse...

Goyer: Right...

Brokamp: ...siblings and thinking, "This could be in my future." What should people be doing before they become a caregiver to get them ready for that possibility?

Goyer: Well, I think about it in five steps. The first thing is to talk about it. Is to have those conversations. And that can be the most daunting part, because it's hard for people to think ahead. It's hard to talk about money. It's hard to talk about care, because no one wants to face the fact they're

going to die someday. I didn't want my parents to die, either. You don't want that, but it's reality. Aging -- it's hard to predict how we're all going to age. We all want to be 99 years old and still volunteering and driving. That's our goal, but it's not going to be the future for everyone.

So you have to start with those conversations. I always say have them early and often; often because things change. Your financial situation changes. Your needs change. Your health changes. Your living situation changes. My dad had almost no peers left. He was 94 years old. He was a veteran of the 10th Mountain Division in World War II and he had been an active member of that Veterans group. There was one member of his group that came to his memorial service, and I was so happy that he had a peer, there.

But all of that is an important part of things, so you want to have these conversations and say, "What are your wishes? What are your goals?" Nine out of 10 people want to stay in their homes at their age. So if that's your goal, what are we going to do to make that possible? We want to talk about the financial situation. It's one of the things people don't like to talk about and yet you need to understand. "Do you have long-term care insurance? What is your thinking as you age?"

Talking about driving is one of the hardest things. Our wheels are our independence. You can talk about it before -- long before -- it's going to happen, and it's a lot easier to talk about. "In the far future, if you can't drive anymore, have you thought about that? Would you rather live somewhere where you can walk everywhere? Do you want to live in a community that has transportation? Or if you want to stay in your home, how are we going to deal with that? We're going to learn how to use Uber or Lyft, or senior transportation. We're going to take you to church and the grocery store." To just start talking about those things and thinking about them, because a lot of time, if we're talking a lot about our parents, they have thoughts about it. They just haven't told you. So have those conversations.

And then come up with a plan. OK, if these are your goals, and these are the resources we know we're going to have, what's our framework? Have a basic plan of where you're going to live. Your healthcare. The quality of

life issues. What kind of socialization are you going to have? And then look at your financial situation. So just a basic plan.

Now, the plan's going to change, so be aware of that and don't freak out about that because things change. But you have a framework. If you go back to the framework, then it helps you when those crises happen and the changes happen, so a plan is really important.

The other thing is to prepare your team. Nobody can do it alone. I mean, the thing that I have learned the most in this experience is I can do anything, but I cannot do everything.

Southwick: Right.

Goyer: Like I have done things I never, ever thought I would do, believe me; but I really can't do everything, and I had to embrace that and be OK with it, because I'm pretty type A. I pretty much want to get everything done. And you can't, so you have to build a team. You look at family, friends, neighbors. Your faith community. Doctors. Paid professionals. Volunteers. It can be a very broad team.

One example is that I've had to do this back-and-forth thing between Alexandria, Virginia and Phoenix, Arizona. And my neighbors, here, in Alexandria I consider a huge part of my team. They mow my grass. They check my mail. I truly couldn't have done it without that. So that's part of your team.

And then you've got to have support, so the community agencies. Learn about what services are available in the community and put together what that support's going to be, as well as caring for yourself, the caregiver. It's always the last thing people think of. You have to realize that it's not selfish. It's just being practical.

One of the things that happened to me (this is a true story). I was running on empty. My car was running out of gas. I got into the gas station and you're just hoping you make it. And after I filled the car up and I pulled out, I thought, "You know, it's interesting. The car actually runs differently with a full tank of gas." It was just that aha moment of, "Oh, I'm expecting myself to run just as efficiently completely on empty at all

times." That was a turning point for me, and that's the analogy I use in my head. OK, what am I doing to fill my tank? A lot of times it's just little, short things. It's five minutes. I'm going to get myself a cup of coffee. I'm going to call a friend. Text my boyfriend. The little things. But then you also have to do bigger things. You have to have the time. A two-hour break, let's say. Or it might be doing something with the person you're caring for.

Dad and I watch musicals. He loved the musicals. He enjoyed the music, then, so I picked out ones that I liked, too. That was a quality-of-life moment for me. That filled me up a bit. And then you have to take more tune-ups and you have to go for a vacation, or a retreat, or go someplace that fills you up. We used to go to our farm in Ohio and that always filled me up. Gave me a big fill-up. And then you have to do the routine maintenance. You have to eat well, and exercise, and go to the doctor, and do your checkups and all of the preventive stuff. And sleep. My top priority has always been sleeping.

Southwick: Oh, me too.

Goyer: Oh, gosh.

Southwick: If I don't get enough sleep, I go crazy.

Goyer: Right. It totally robs you of your ability to cope. You just cannot. Everything is worse when you're tired. And I'm a nine-hour-a-night person.

Southwick: Oh, I'll take 10. If you're going to give me 10, I want a 10.

Goyer: All right. Let's do 12.

Southwick: Why not?

Goyer: We'll go to 13. Those are the things. The family discussions. Preparing your team. Making a plan. Building support and then caring for yourself. One of the things about caregivers -- you shared some statistics. There's an average of \$7,000 a year caregivers spend out of pocket on caregiving.

Brokamp: Wow!

Goyer: Most of it goes to household expenses. Paying for your loved one's rent, or utilities, or just stuff in the house. But also, things like medical expenses. That's the second most-common thing. And you're going to spend this money on food. On clothing. I bought all my dad's clothing. Medical equipment. All of that. If you're long distance, the average is \$12,000.

Southwick: Oh, wow.

Goyer: And if you're caring for someone with dementia, it all doubles. And I can tell you I spent far more than that every year. It really varies, and so it's something to think about; not "I can't do this because I don't have the money," but "how are we going to do this?" There are ways to work around that.

Brokamp: Part of it, I assume, is what you spend out of pocket, but also being able to access the financial resources of the person you're caring for. What's the best way to do that, particularly as there can be some legal issues. You mentioned power of attorney earlier. There could be issues of when you're spending money from your dad's account the siblings may question those expenses. What's the best way to do that process so that's not all on you?

Goyer: That's a really tricky question. And most of the time there's one person in the family who they want to do that. And if your loved ones haven't done this planning and they need to do the planning, designate who's going to be the power of attorney and who's also going to manage the estate when they're gone.

But generally there is one person who it points to in terms of managing things. It should never be one person's complete financial burden to carry. Let's say we have a situation where there are parents and you've got four siblings. Find ways that everybody can contribute.

But first, as you say, you have to maximize your parents' income and that sort of thing, so you want to be aware of and have a handle on their income, whether it's pensions or retirement funds. Any benefits they may

receive. My dad was a veteran, and so he got Veteran Aid and Attendance benefits which made a huge difference for us; but I had to go through the process of applying for them. He didn't know anything about those benefits. Most people don't.

And so finding all those different types of income to make sure that you're maximizing what they can pay for before the family starts pitching in. And that might include long-term care insurance. I can't tell you how many times people have told me this. They had long-term care insurance and the kids had no idea they had it. And if they forgot about it -- if it's paid automatically or whatever -- it's a huge waste of money. So finding out about that. Getting all the legal things in place.

And then there's practical aspects of managing that money. The bank accounts. How do you access everything? Your retirement or your investment accounts. What are the legal aspects of it? I ran into some things where I thought my power of attorney would do everything, and the bank wanted their power of attorney. We had sold a property that belonged to my parents and the house was in a living trust; so the payment for the property went in a [checking account] living trust. We didn't have a living trust checking account, so we had to open a new account to deposit that check. I couldn't deposit it just in my parents' account.

And my mom had, had a stroke. It was very hard for her to write her name. My dad could do it. He was OK. His writing was starting to get hard to read. So we got the lawyers involved and, in the end, it was, "Well, they shouldn't do this, but they can. They can require it." So they came to the house. It took my mom probably an hour to sign all those documents. That shouldn't happen, but those are the surprises.

So really try to talk with your lawyers about any scenarios. One of the things that my dad and mom did was before my dad wasn't able to do those kinds of things, my mom had aphasia, so she couldn't speak very well. Thankfully he was still living. We could do the things where we would call up all the people he was paying money to and he would say, "My daughter has authorization to deal with my account." Sometimes they would do that just as a phone call. Sometimes there are forms you have to fill out. Sometimes both. It can get very complicated. And then

sometimes you can just set things up online, but then you have to know the passwords, and the pin numbers, and all of those things, as well.

Brokamp: Right. This emphasizes some key points. First of all, ideally before you need the care, you've already laid this out somewhere in some documents where you can find all the insurance. Where your bank accounts are. Even maybe the passwords for things like that -- to write it up beforehand. And to get professional legal help for doing all this.

And I assume it was complicated partially, in your situation, by being in different states, because different states have different laws about handling this stuff.

Goyer: Yes, absolutely. And sometimes people get in a situation where their parents are even living in different states. They're not divorced, but they're living in different states, so you have to be careful about that, as well. So if you're living in Virginia and your parents are in Arizona, you need a lawyer in Arizona managing their things and telling you what to do there.

Brokamp: Let's say someone's in this situation suddenly. Often this happens because someone goes into the hospital and they then have to be taken care of. Just from a triage standpoint, what are the first steps someone should take when they suddenly become a caregiver?

Goyer: First you have to assess the situation, and you want to assess it in terms of what your loved ones' needs are, first of all. What is their health condition? Really try to get a good handle on that and understand going forward what's going to happen. That's where you talk to the doctors. You talk to the social workers. You talk to the nurses and try to understand what their capabilities will be going forward, and what kind of rehab they're going to need. Is my dad ever going to walk again, or is he going to have a hard rehab and that's our goal, is to get him walking again? To understand that situation.

And then, in any kind of a crisis like that, you have to figure out roles. So what's your role at that point? Are you the person who's got power of attorney so you know this is your role? It's to take charge and organize

everyone, or has that not been discussed? You're one of siblings and then everybody's trying to figure out their roles.

I do think it's really important to figure out clear roles, and even if they're temporary, get a clear idea, because otherwise you get duplication. You get, "Well, I looked this up and found this." Or, "No, I think we should do this." It doesn't mean that you can't discuss decisions and that sort of thing. I never made a decision without talking it over with my sister, but I had the ultimate authority to make the decisions just because legally I did.

You want to figure out those roles and then you've really got to gather all those documents. Someone has a fall. They're in the hospital. Everything changes. What are we going to do now? Where is the power of attorney? It's been with my sister. I knew she had sent me a copy of her power of attorney. I was so focused on caring for my parents, I didn't even look at it. I just knew I had it on my computer. I then came to find out she hadn't signed it.

So I was able to go to her house and dig through documents and finally found an older version that she had signed and it still designated me, so it wasn't terribly different. I was lucky. But I didn't know where anything else was, so we had to just search and search through paperwork. That was huge stress on top of this situation.

So try and find all those documents. Locate everything. Go back to your plan. If you've been prepared, you will have some kind of a framework of, "If this happens, we'll do this," as much as possible. Make sure that you do that and then get help, especially in a crisis. It's kind of like having children. You're not really born knowing how to do these things, so you need to get help.

Talking to the hospital's social worker or discharge planner is really key. I always say to start talking with a discharge planner the day after you're admitted. Don't wait until the very end, because you're going to need time to research options. Make decisions. Maybe find a different living situation or a temporary rehab. They can do a lot of things. They generally have lists and they can connect you with community services.

Everywhere in the country has an Area Agency on Aging. It's part of the Administration on Aging from the federal level. It goes down and then every state has a State Unit on Aging. Then they divide up the state in these areas. And they're the ones who really coordinate home-based and community-based services. They fund a lot of services. Sometimes they actually provide services. They know the lay of the land.

It might be a multicounty area. In Arizona and Phoenix, Maricopa County has one Area Agency on Aging. But that is a great call to make to find out what's available in your loved one's area. For example, maybe adult day care is an option, where they can't be home alone all day anymore, and I can't send them home to be home alone, but I can get them out of the hospital and get them home if I know that they're going to adult day care every day and then we have other things in the evening.

So find out what's available. Reach out there. Your Area Agency on Aging you can find by going to the Elder Care Locator. That's at www.ElderCare.acl.gov. And I can repeat those websites later. But those are kind of the big things.

And especially in a crisis, we're not prepared. Our loved ones aren't prepared, but we're not prepared, so think about what else is going on in your life. Caregiving doesn't happen in a vacuum. You've got work, and you've got your home, and you've got your family, and your pets, and your volunteer work and whatever your obligations are. So in that crisis time (somebody's in the hospital), be sure to think of how you're going to deal with that.

Sixty percent of family caregivers are working, so that's a big issue. It's good to know that if you know that you're moving into these years, just look into what options you have at work. Is there any flexibility? Can I telecommute? Is there caregiving leave? AARP now offers that for their employees and it's a trend we're seeing with extra time off just for caregiving for someone else. Not your own sick time. So find out what your options are for work. Can someone back you up? And then you're home. What are the plans? Who's going to feed the dog? All those types of things.

Brokamp: I assume, especially at the start, the caregiving falls to the person who's basically geographically closest to the person who needs the care.

Goyer: Mm-hmm.

Brokamp: What are some ways that people who are not close by can still help out and stay connected?

Goyer: Long-distance caregiving is a big question, and as I mentioned, the costs are higher for long-distance caregivers. They tend to be. And that's probably because first they're spending money on plane tickets or driving to get to visit; but they're also paying for services they might be providing themselves if they live nearby.

So you could be in a situation like my dad with his parents was. He was 2,000 miles away and he was the only child. That's one way. It could be you're a long-distance caregiver and there are other people who aren't nearby, so you still need to find out what to do. It's not a "Get Out Of Jail Free" card. There's something that everyone can do.

My oldest sister, before she passed, was so ill so much of the time and she couldn't contribute money. She couldn't come and help. But I asked her to call Mom and Dad every day. And she did, even though she didn't feel good at all. She called, and talked to them, and they loved that, and it gave us a break, and it helped give them quality of life, and she was contributing.

It might be that there are other things you can do. Often the person that lives at a distance does manage finances, because that's something where you can do so much online now. That might be a role that you can play. It might be that you do research online. Over the years I would ask my best friend, who lives here in the DC area, "Can you look up what I can do about this? This new diagnosis?" That's helpful. Somebody has to do it, so even if you're not right there, you can do that.

Other things you can do is when you do make a visit, you have to maximize it. When you go to your loved one's house, you need to assess the situation every time. Look for red flags. A lot of times what I tell

people is if they see there's mail piling up, Mom and Dad might need some more help. They're not able to keep up with it, and that's a good clue that maybe they're not managing their finances because they're not opening the mail or there are unpaid bills. Or double-paid bills -- bills that, "Oh, I didn't pay that," when they paid it three times. So understanding what that situation is. You've got to look for those red flags. Is the house being taken care of?

Or personal care. That's a big one, actually. When you're not there with the person, it's sometimes hard to know that they're not taking a bath anymore, or they haven't changed their clothes in week. Little things like that which are clues to either cognitive changes, depression. Physical ability -- it's too hard to do the laundry. They have visual problems. They can't see. They don't realize their clothes are dirty. So checking on those things. And then meeting with the doctors and the aids and getting a good handle on things.

Do those things when you're there, but you have to have someone who's your eyes and ears on the ground if you're not there. If it's not another family member, then neighbors sometimes really help out a lot. Someone from a Faith Committee. The community. A volunteer.

There are also geriatric care managers. They're sometimes called "aging life specialists" or just care managers. They're people who will be you on the ground. Early on with my mom and dad, I would come back here. I would be gone, sometimes, for two weeks at a time. So I had someone who knew where everything was. If Mom or Dad had to go to the hospital, she could go right away until I could get there. That was like my backup. A lot of people are relying more on someone like that as our families are so mobile and we aren't there all the time.

And then the last thing is technology. It's huge. It's made a huge difference in long-distance caregiving because there's so much you can do, now, to stay in touch. To monitor medication. To keep the house safe. Video monitoring. Just all kinds of things you can do.

Brokamp: There are some more services that really facilitate the communication in a lot of ways with everyone. Like lots of Helping Hands. AARP has an app that does a lot of that.

Goyer: There's many apps. Technology has made a huge difference in caregiving, in general, whether you're long distance or not. The apps are great for care coordination. CaringBridge. Lots of Helping Hands. CareZone. There's a lot of apps that play different roles. But then also just using apps. I use Evernote a lot. I use Dropbox. The apps that I have used the most are the ones I use in all the areas of my life. I have a to-do list app I use. I have all of those.

For example, in my Evernote I have a copy of the power of attorney and all the documents because it's quicker for me to access than having to get my computer. And so people are finding different ways to incorporate caregiving into the apps and things that they're using. But the nice thing about the caregiving apps is it puts it all in one place. You can have shared to-do lists, and task lists, and you can assign things to people. You can have a shared calendar and really keep track of what's going on in the caregiving situation.

Brokamp: Any other final thoughts or final pieces of advice?

Goyer: Well, again, thinking about technology. Think about safety, too. My dad used to get out of bed, at night, to go to the bathroom and then he'd get lost in the house. So I got a floor mat that has an alarm. The minute he puts his feet on it, a little beepy thing would go off and I had an audio monitor in there that I could hear in my bedroom. I would know he was up, and then I could jump.

Then I got a video monitor and then I could really tell if he was just rolling over in bed or he was really going to get up. So investigate those things. I really think you have to embrace technology. There are people who say, "My loved one can't live at home anymore because they keep going out the door and I'm afraid they're going to get lost." Well, get an alarm on the door. They're inexpensive. There's a lot of different things that you can do.

And just really reach out. Caregiving can be very isolating, so it really helps to connect with other caregivers. AARP has an online community that you can get in 24/7. Whenever it's convenient for you. I'm in there a lot along with other experts. You can post questions and get feedback and that's just at [AARP.org/caregivingcommunity](https://www.aarp.org/caregivingcommunity). And AARP also has a full

family caregiving website. So you're going to find articles on everything we've talked about and more. I have a column. We have other expert columns. Finances. Health. Caring at home. Caring at a facility. All kinds of different things. And that's aarp.org/caregiving.

We have a free publication that's a great place to start. It goes over those five basic things that I talked about when you're getting started with your situation and creating your plan and that's called "Prepare to Care." Again, aarp.org/PrepareToCare. Or you can call the toll-free number at 1-877-333-5885 and request a print copy of that publication.

And then, of course, I cover all this in my book, *Juggling Life, Work, and Caregiving* in great depth. I have checklists, and tip sheets, and everything practical. I think that's the thing. Keep it practical, but look for the joy, and that's my final tip. For me, that's what got me through. Those joyful moments are what fill your time and keeps you going and I'd remember why I was doing this.

Looking back, now, I know that's what kept me going. I had to proactively create those moments of joy a lot of times, but also just notice the little things. My mom's smile when I'd tuck her in bed at night and singing with my dad. I have a lot of videos on my website of fun, silly, crazy stuff. That's what it's all about, right?

Brokamp: Right.

Goyer: It's all about the quality of life.

Brokamp: That's great. Amy, thank you so much for coming in and helping us.

Goyer: Thank you. Thanks for having me.