

## Caring for a Parent From Far Away



MARY KANE, *Kiplinger's Retirement Report*, November 2017

Dave Nickerson's mother, Catherine, is almost 95, but he says she's as independent and self-sufficient as ever. A former schoolteacher, Catherine has lived for 65 years in the same house where Dave grew up, near Boston. And she's made it very clear she intends to stay there. "She's embedded in the community," Dave says.

Dave helped remodel the house a few years ago, so his mom's living space is all on one floor. Supportive neighbors check in on her regularly. Dave oversees her medical care and manages the bills. He says he feels he's on top of her situation, even with the one major complication that he deals with on a daily basis: He lives 1,800 miles away, in Houston. "I moved out of that house back in 1972," says Dave, who is 65. "Now, I'm up there regularly. Her emotional well-being and health are tied into remaining in that home. I intend to support her in that manner for as long as I can."

Caregiving for an elderly parent or relative is hard on anyone. But for the nation's seven million long-distance caregivers, "there's an extra layer of stress," says John Schall, who heads the Caregiver Action Network, a Washington, D.C., nonprofit. He's a long-distance caregiver himself, too, for his mother in Livonia, Mich. He calls it "the worry factor"—you're not there to see for yourself if the parent ate a good lunch, got out for a walk or took medicine correctly. You wake up in the middle of the night, anxious about missing something. "The not knowing is even a greater stress," Schall says.

Around the holiday season, adult children sometimes realize a parent may need more help. Home for Thanksgiving, you might notice things are amiss. The refrigerator is nearly empty, or there's expired food. The house is dirtier than usual. Unopened mail is piling up. "When you are visiting at the holidays, and maybe seeing some changes, it's a perfect time to have some meaningful conversations, whether it's with elderly parents, siblings or everyone together," says Ruth Drew, director of family and information services for the Alzheimer's Association, in Chicago. She recalls working with a family where a sibling set up a formal PowerPoint presentation after Thanksgiving dinner to plan for a parent's care.

You don't need to go that far. But if it's time to step in, you should prepare for your new caregiving role. You'll face financial challenges, from handling a parent's bills to paying out of pocket for travel and costs for caregiving, which can average \$12,000 a year, according to a

recent AARP report. You'll need to spiff up your organizational skills to get a parent's medical and legal paperwork in order, and be ready to jump in as the advocate for his or her medical care. If you're still working, you'll pile these duties on top of your full-time job.

The good news is you can break down your caregiver role into stages, and use strategies that have been proven successful for each stage. Early on, for example, set up a network of friends and neighbors to help you keep tabs on your parent or loved one.

Worried about not being there with Mom at the doctor's office? Think about hiring a geriatric care manager to accompany her and to oversee her prescriptions. Take advantage of technology to organize caregiving and keep in touch. As your responsibilities increase, seek support from local resources or online caregiver groups.

And take a deep breath—start out by accepting that you can't do everything at once—and that you shouldn't even try. Give yourself credit for starting to plan, instead of waiting for an emergency, such as a fall. "Step back, and recognize that this is going to take some time," says Leah Eskenazi, director of operations at the Family Caregiver Alliance, a nonprofit in San Francisco aimed at supporting caregivers. You'll need that time at the beginning just to gather information and understand what's happening, she says. "There's a difference between trying to do things fast and trying to navigate things well."

## Get Started

Start small, and build up some trust, before taking your first steps, Eskenazi says. Work with your parent to find out where all the important documents and assets are, from bank accounts to safety deposit boxes. But don't come barreling in and demanding information. You may be the most accomplished financial whiz in New York, "but your mom may still see you as the 16-year-old kid who crashed the car," Eskenazi says.

Visit on a regular basis, if you haven't been doing so already, and launch a conversation in a nonthreatening way. Mention you've been thinking about what to do in an emergency. "You can normalize it by saying, 'This is something I was going to do for myself, too, which is updating my own information and making sure the right people have access to it, in case, God forbid, I got hit by a bus,'" says Drew, of the Alzheimer's Association. "And 'if it happened to you, I wouldn't know where to begin. Can we talk about this stuff?'"

Or mention recent financial data breaches as a door opener to discussing the need to protect one's accounts.

Ask about two types of powers of attorney, one for decisions on health care and one for finances, says Katherine Pearson, an elder law expert and a Penn State Dickinson Law professor. If your parent doesn't already have those documents, help get them prepared. And brace yourself for a blizzard of other paperwork: life insurance, retirement accounts, bank statements, deeds, wills

and trusts, a list of passwords, and more. Print out the "Where to Find My Important Papers" checklist from the [Family Caregiver Alliance's website](#) and take it with you on a family visit. If you need more advice, find an elder law attorney at [www.naela.org](http://www.naela.org). Once you have access, you often can handle a parent's accounts and pay bills online. But if you need more help, consider hiring a daily money manager (see [Managing Your Money in Old Age](#)).

Next, settle sibling issues. Decide who will be responsible for routine day-to-day matters and when to consult with others. Be realistic about the family dynamic. "You may have to promise—and live up to that promise—not to second guess your brothers and sisters, especially if they are the ones living closer to Mom or Dad," Pearson says. "Learn and practice the art of biting your tongue, before you make a suggestion about how to do it 'better.'"

Or, accept that you may be the one taking on the biggest burden. Nickerson and his wife, for example, mostly manage his mother's care, even though he has brothers, including one nearby. Nickerson says he's not angry—he just does it. "We can handle everything financially and emotionally," he says. "I'm fine with it."

On the health front, arrange for a full medical assessment during one of your visits home, to rule out any medical causes for some of the changes you're noticing, Eskenazi says. To avoid roadblocks later, ask the doctor if your parent needs to sign a consent form giving the doctor permission to speak with you about your parent's medical issues, even when your parent isn't present.

Finally, enlist friends and neighbors. Deborah Fins, a geriatric care manager in Worcester, Mass., suggests giving out your business cards or sharing your e-mail at a parent or loved one's place of worship or a favorite coffee shop. Encourage acquaintances there to call you if they notice changes in a parent's behavior or haven't seen him or her in a while. Ask neighbors to check in regularly, particularly during bad weather, when strangers may knock on doors looking for snow shoveling jobs, for example. "I tell children living out of town that you might want to reach out now to start to build your support network," Fins says.

## Stay Connected

Technology can be helpful. But don't rush into buying the latest expensive monitoring gadget, says Grace Whiting, chief operating officer of the National Alliance for Caregiving, a research and policy nonprofit, in Bethesda, Md. Use an app such as [Care.ly](#), a free care coordination tool for family members and caregivers to track visits and share updates. For safety, a parent might be willing to wear a personal emergency response device if it's shaped like a bracelet, or carry a mobile device with a GPS in her jacket or purse. Or try [Care Angel](#), an app that uses technology to make check-in calls to a parent and collect information to report back to you.

Check with a parent's health care system and pharmacy for apps they offer, so you can keep tabs on health care visits and prescriptions, Whiting says. And if your parent is in a nursing home or

assisted living, seek permission to use teleconferencing to get progress reports from the staff and ask questions, says Lynn Feinberg, a senior strategic policy adviser for AARP's Public Policy Institute.

## Get More Help

If you decide monitoring from a distance isn't enough, consider hiring a geriatric care manager, also known as an aging life care manager. They provide on-the-ground care, from home visits to assisted-living oversight, to hiring and overseeing caregivers, to accompanying parents or loved ones on doctor visits.

Phil Pfeiffer, 62, who lives in Johnson City, Tenn., uses a care manager because his mother, age 89, wants to stay in Pittsburgh. It's been a big help in making sure she's doing well in her nursing home, he says. "There have been any number of situations that have come up where the care manager has stepped in," he says. "The care manager will note that there's a sore here, or she's not being propped up right."

He also used the agency to vet and hire local caregivers when his mom lived independently. "It's not something we could have done on our own without considerable difficulty," he says.

You can find a local care manager through the [Aging Life Care Association](#). Many charge between \$100 and \$300 an hour, and insurance doesn't cover the cost. Care managers can be nurses, geriatric care specialists or social workers. Decide if you want to use a team of managers or a solo practitioner, based on your parent's medical and other needs. And some agencies, such as Holistic Aging and Options for Elder Care, the Pittsburgh agency that Pfeiffer uses, are beginning to specialize in alternative medicine.

## Expect Change

Even if caregiving from a distance is going well, you can't expect the status quo to last forever. At some point, you may need to move your dad to a geriatric care facility or move him in with you. Instead of ignoring the possibility, find out your parent's or loved one's preferences. Consider visiting a few facilities together. Emphasize that you're not pushing for an immediate decision but instead creating a list of options for when they are needed.

Sometimes emergencies can force a change. Maggie Garcia, 47, lives in Tampa, but she was raised in St. Croix, where her parents, Luis, age 73, and Olga, age 69, live. For three days after Hurricane Maria in September, she had no word of their condition. She eventually learned her parents were fine.

Maggie's parents have been through hurricanes before, so she and her siblings made sure they were stocked up on water, canned goods, batteries and other needs, and she knew who to reach in St. Croix. You may not encounter a major weather disaster, but you should prepare for smaller

emergencies, from a car accident to a fall. Fill out the "Key Contacts" worksheet at the [Caring from a Distance website](#) so you won't be scrambling for phone numbers in a crisis.

The hurricane also heightened Maggie's resolve to have her parents move in with her in Tampa, she says. Her father was diagnosed last year with Alzheimer's. Maggie, a medical assistant, says she often is the only one who can calm her father down, by talking with him or playing music. "My dad says he's still not going anywhere, but my mom realizes she can't do it all on her own, so she is very much wanting to make the move."

For help in relocating a parent or a loved one, see the online community resource finder at the [Alzheimer's Association website](#), review its page for long-distance caregivers, or call its 24-hour, 7-days-a-week helpline at 1-800-272-3900. The [Caregiver Action Network](#) offers similar resources for other disease-specific caregivers.

## Support Yourself

You need to take care of yourself as well as your parents or loved ones. Nickerson, the Houston caregiver, says he does cardio workouts every day to keep his mood up. Pfeiffer says he also works out "to keep myself sane." Garcia listens to music, and she joined an Alzheimer's Association support group.

Check with your employer. Some offer geriatric care manager services in their employee assistance plans, which could help you with the time-consuming task of handling insurance and paperwork. But be aware that only three states so far have implemented paid family and medical leave, and the availability of caregiver support policies varies widely among employers. Still, don't quit your job, if at all possible. Most likely, you won't find financial support to replace your lost wages, says Eskenazi, of the Family Caregiver Alliance.

You may feel guilty about your time crunch. But realize that your caregiver role has limits, and you can't control the progression of a parent's or loved one's aging or disease. You can try to make your parent's life as safe and as comfortable as possible, and feel a sense of satisfaction in your effort. "For me, it's a matter of honor," Pfeiffer says of his long-distance caregiving. "You do things sometimes because they're the right thing to do." [The Law Offices of Elovson & Tenore](#), is a firm specializing in elder law. We can be reached at [203-336-2566](tel:203-336-2566) or by email at [ct@connecticutelderlaw.com](mailto:ct@connecticutelderlaw.com).

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