

Finding a caregiver



What to look for when hiring someone to help.

by Shara Rutberg



Important attributes to look for in a caregiver include reliability, respect, trustworthiness and compassion.

Juliet Cuorato's hired caregiver, Hafida Kaoukaji, helps Cuorato in her Philadelphia apartment 45 hours a week. Cuorato appreciates how Kaoukaji cleans the kitchen and bath exactly the way she likes it, how she understands the different symptoms of Cuorato's secondary progressive multiple sclerosis and how she can best help when the symptoms flare up. Cuorato appreciates how Kaoukaji even drove her home from the hospital after her surgery and helped her stick to her daily schedule of physical therapy exercises.

But what brightens the 61-year-old's voice the most when Cuorato talks about her caregiver of 10 years is not how Kaoukaji cleans her kitchen, but what she makes in it. Kaoukaji has introduced Cuorato to fabulous dishes from her native Morocco. "She's a very, very good cook," Cuorato says. "Not just good—professional level. Her food is amazing! It's like I have a pastry chef!"

Kaoukaji works for Cuorato through a home care agency, one option for people with MS who do not have a spouse or partner who is able or willing to help with the sorts of tasks that people with MS often need or want.

Jason DaSilva, who lives in New York, works through that state's consumer-directed personal assistance program and hires his own crew of four to six independent caregivers. Jackie Garrison, of Pineville, Louisiana, relies on her 16-year-old daughter, Emily, as her main caregiver.

These are three resources—a home care agency, a state-directed program, and family—that people living with MS have found work for their individual situations.

Cuorato's rheumatologist referred her to JEVS Human Services, the nonprofit agency she uses to employ Kaoukaji. "It was a good thing he did, because I wouldn't have known where to start," Cuorato says. There are more than 700 home care agencies across Pennsylvania.

"It can be very overwhelming," says Juliet Marsala, vice president of Community Health and Long Term Supports at JEVS, which serves more than 30,000 people in the mid-Atlantic region. "What programs are out there? Which one is right for you? How can you pay for it? It can be daunting," she says.

Start with the money

Begin by finding out whether your health insurance or your long-term care insurance covers home health care. If you have Medicare, you may qualify for home health care if you meet [certain criteria](#). In some states, Medicaid can pay a family member to work as a caregiver. If insurance does not cover home care, determine if you can afford to pay for it out-of-pocket, or if community funding might be an option.

Public funding for programs like Medicaid varies widely by state. DaSilva's situation is a frustrating—and heartbreaking—example. Living in New York, DaSilva, 40, an Emmy Award-winning documentary filmmaker and activist, is able to finance caregivers in his apartment

through a state-based program that allows him to choose his own aides. “My caregivers not only help me with everyday care,” says DaSilva, who uses a wheelchair and has blurry vision and limited use of his hands. “They also help me maintain my independent life and business, doing things like helping with email.” However, DaSilva wants to move to Texas to be closer to his young son, who lives there with his mother. But while New York is ranked in the top 15 states in terms of disability care, “Texas is dead last,” DaSilva explains in a short film that appeared with his [op-ed in the New York Times](#) about what he calls “the disability trap.” To receive the same type of care in Texas that he does in New York, DaSilva would have to live in a nursing home and give up his independence.

Support organizations

The National Multiple Sclerosis Society’s MS Navigators can provide a variety of resources and point you in the right direction for your situation. Local public support agencies can help you wade through your financial and program options, Marsala says. “They’re a great place to start.” Every state has local centers for independent living and area agencies on aging. The United Way’s 2-1-1 and the individual states’ departments of human services are other helpful resources, along with the Eldercare Locator from the U.S. Administration on Aging, which connects older adults, families and caregivers to community resources.

Resources for finding care

- [U.S. Department of Health and Human Services](#)
- [National Association for Home Care and Hospice](#)
- [Family Caregiver Alliance](#)
- [Center for Independent Living](#)
- [National Association of Area Agencies on Aging](#)
- [United Way 2-1-1 Referral Service](#)
- [Eldercare Locator](#)

The agency route

While Cuorato feels “very, very, very fortunate,” for her current caregiver, the first two experiences with the caregivers she found through an agency did not work out. She found Kaoukaji on her own through a recommendation of the caregiver of an acquaintance in her neighborhood and was eventually able to sign her up for employment through JEVS. The agency handles recording hours, payment and billing. (The cost of care is covered through a combination of state and federal programs).

Working through an agency also means there’s often a supervisor to oversee the situation and to provide back-up attendants in case the main caregiver cannot make it to work, says Marsala. Some agencies also provide continuing training programs to caregivers. “When selecting an agency, ask pointed questions, like ‘how do they handle snow emergencies?’ For example, some provide Uber and Lyft vouchers to caregivers,” she says. Be sure to select an

agency that runs background checks on caregivers.

Once you do select an agency, be very open about what you want in a caregiver, says Marsala. “The more information you give, the better an agency can do at matching. And don’t be afraid to change agencies if something’s not going right.” Working with a paid caregiver is very different from having a family member or friend help you. “They should be working hard at the direction of the person, respect professional boundaries and confidentiality, trained in universal precautions and have basic awareness of medication distribution needs,” says Marsala. Another big difference is that a hired caregiver (through an agency) has a supervisor to support the relationship.

Whether you’re working with a paid or volunteer caregiver, such as a family member or friend, it’s important to review the services that will be provided and discuss each person’s expectations, says Maryann Ludwig, chief strategy officer of JEVS at Home, the home care affiliate of JEVS. “Volunteers are generally less skilled than trained caregivers, so they may not be able to assist with all activities. If that’s the case, it’s important to know that from the start,” she says.

Choosing a caregiver

When interviewing a potential caregiver, take the time to write down your specific needs in a job description you can share with the candidate. Find a job description worksheet on the Society’s website at ntlms.org/hiringhelp.

Don’t be tempted to not mention chores that may embarrass you, like changing a catheter bag or helping you bathe. Talking about these things openly is essential to employing someone who will be able to meet your needs. Have a family member or friend with you and if possible, do the interview outside your home to protect your privacy.

Ask about the applicant’s work history. “Some people prefer a highly skilled caregiver with a lot of experience,” says JEVS at Home’s Maryann Ludwig. “I don’t believe that experience is the most important factor to consider. It’s more important to find a caregiver who is reliable, respectful, trustworthy and compassionate. These are attributes that generally cannot be taught.”

Make sure you can communicate clearly in your preferred language. Check that candidates have reliable transportation. Ask situational questions, like “How would you go about doing laundry?” and listen for an answer that indicates they would start by learning your preferences about how you would like to have things done, suggests Juliet Marsala, vice president of Community Health and Long Term Supports at JEVS at Home. Putting your preferences first is critical, she says.

Then ask yourself a key question: Would you feel comfortable with that person as a

caregiver? “You’re going to have a very close relationship,” says Marsala. “That caregiver will become a significant part of your life, so take the time to really interview to your needs.”

Watch out for an applicant who is late to the interview and for applicants with no references. Also, beware of applicants that direct their questions to a family member instead of you, or anyone who asks you if you’re willing to sign a blank time sheet. When you do choose a caregiver, have them sign a written agreement outlining their responsibilities.

Family member caregivers

Emily Garrison, 16, has been her mother Jackie’s main caregiver since her MS diagnosis when Emily was 12. Emily’s sister Riley is 15. Jackie’s husband is undergoing treatment for prostate cancer and is less able to help. Jackie says that with Emily, “There’s a level of comfort that I can’t describe.”

While Emily cooks dinners and assists with Jackie’s artisan soap business, some of the most important help Emily provides is mental and emotional. When side effects of Jackie’s medication wracked Jackie with pain through the night, “I held her hand, and told her it was going to be OK,” says Emily. She often helps her mother sift through “word salads,” what they call the jumble of words in your mind’s bowl that can be a symptom of MS. Often, her mother picks out the wrong word. Emily usually knows what one she’s reaching for. “Almost like a translator,” she says.

Emily says she enjoys caring for her mother, though it can be difficult to “always be helping, without a lot of break time.”

The most critical piece of support Emily provides Jackie, is acceptance. “She seems to recognize that I feel like I’m not the mom she signed up for. She can see that I’m doing the best I can with the hand I’m dealt,” says Jackie.

Knowing how much to ask of her daughter as caregiver is a “difficult balance,” says Jackie. “At the end of the day, she’s still the child and I don’t want her to not do something because she feels obligated to stay with me.” Plus, she says, like herself, her daughter is unlikely to ever complain about helping. The key, she says, is also what Marsala, Ludwig and Cuorato say is critical for maintaining healthy caregiver-client relationships: good communication. “No one can read your mind,” says Cuorato—even people who bake heavenly pastries.

Shara Rutberg is a writer in Evergreen, Colorado.

For information on hiring a caregiver, visit [Hiring Help at Home](#).

The National Multiple Sclerosis Society can provide information on resources about caregivers and support for family members who are care partners. To learn more, [contact the Society](#) or call an MS Navigator at 1-800-344-4867.