



TRANSCRIPT

Feeling at Home with Home Care

As a loved one's dementia progresses, there comes a time when most caregivers need help. The person with dementia may no longer be able to handle simple daily routines, such as meals and toileting. Or the caregiver may simply not have the physical strength to cope without risking their own well-being. In some cases, the caregiver may feel emotionally depleted, physically drained—or both.

There are many options available, but this discussion focuses on *in-home care*. By this I mean a caregiver who comes into your home to help with care, one on one. Their care may span a continuum from companionship and supervision to total hands-on help with activities of daily living such as bathing, dressing, and toileting. Caregivers can also help with laundry, housekeeping, meals, and errands. They can read with your loved one, do puzzles with them, or go for walks in the park. I had a client who had lived in France and loved everything French. Her husband hired a caregiver who, in addition to basic caregiving tasks, had conversations in French, and explored famous French sights, art, and music on an iPad.

Once you decide on the type of care you want, where do you find it? There are basically two sources for caregivers: You can hire a caregiver directly, known as private caregivers, or you can work with a reputable agency. I strongly recommend the latter. I have known many excellent private caregivers over the years. But when you hire privately, you become the employer and you assume all of the responsibilities and potential risks. You are liable if the caregiver gets injured on the job. You are responsible for managing payroll and taxes, and understanding the rules of overtime, among other things. If there's a performance problem, you need to deal with it. When the caregiver is sick or goes on vacation, replacement is up to you.

On the other hand, if you work with an agency, the caregiver is *their* employee, and the agency assumes

the responsibilities of being an employer. Given the benefits, why would anyone *not* work with an agency? Usually it comes down to finances. Home care in general is expensive. And there's an impression that hiring directly is less expensive than going through an agency. But the tables can quickly turn if a caregiver breaks a leg on the job, or sues you for not paying overtime correctly. In fact, bottom line, some caregivers charge the same or even more than agencies. If you do choose to hire privately, at the very least check with your homeowner's insurance company about a rider to cover employees working in your home. It's also a good idea to draft a contract to formalize job expectations, salary, schedule, and time off.

Or you can hire a professional agency to handle all of this.

Once you decide you want to work with an agency, how do you find a reputable one? Start your search by asking friends who have hired in-house help, or your doctor's office. The resource person at your local senior center may be able to help. You might call the Alzheimer's Association, Family Caregiver Alliance, or your local Agency on Aging.

Once you have a few agency names, look at their websites to get a sense of their approach to caregiving and range of services, then start making some calls. I recommend starting a folder and taking notes.

In your initial call to each agency, you'll want to ask a lot of questions: How long have they been in business? What range of services do they provide and what is the fee structure? Do they have a minimum number of hours for service? Can they provide overnight and live-in care? Will they provide a consistent caregiver? What do they do if a caregiver calls in sick? Can you yourself interview a couple of different candidates for the job? Your particular situation will guide your questions, for example, if your loved one has mobility problems.

Once you've decided on the agency, be prepared to give

as much information as you can to help them find the best caregiver for you.

They should be asking you a lot of questions about your specific situation and your loved one's care in order to clearly define and clarify the caregiver's duties. They might ask whether you think a male or female caregiver would be more successful. Should it be someone who is high-energy and engaging or quiet and unobtrusive? The "match" is everything. Having said this, I have experienced situations where the caregiver we thought would be the best fit turns out not to be—and the one we never thought would be accepted by the family turned out to be "the one." So the moral is: Keep an open mind.

The agency should allow interviews with candidates, and you should take advantage of them. Prepare a list of questions, and for the sake of comparison, ask each candidate the same questions. You'll want to know their experience working with people with dementia. How long have they worked with previous clients? What is their favorite part of being a caregiver? The most frustrating/stressful? You get the idea. You may have a difficult time choosing and if so, go with your gut. Although we hope that the first caregiver is the perfect match, in reality you may have to try a few before settling in with the right one. I should add here that flexibility is important when it comes to the caregiver's schedule as well. If the exact days or times are really not that important, go with what works best for the caregiver of your choice. A happy, respected caregiver will be much easier and more enjoyable to work with.

Now that you've selected the agency and the caregiver, and determined the schedule and tasks, what can you do in the beginning, on that first day, to set the stage for success?

- First, it helps to have a list of what you'd like done during their time with your loved one. Don't assume the caregiver knows exactly the tasks you have in mind, even if you've discussed them with the agency.

You'll want to discuss your loved one's preferences and dislikes, as well as strategies you use to handle resistance. For example, turning on the heater in the bathroom and a little music make all the difference in getting your loved one in the shower. Maybe showers never happen in the morning, but work better after lunch. To succeed it's important to communicate with the caregiver.

- Second, give the caregiver a full tour of your house and where to find the necessities for care—gloves, wipes, Depends. What are your loved one's food preferences? If they go out for a walk, do they need a key to get back in the house?
- Third, where do you keep emergency information? (And if you haven't written this out, now is the time to do so, along with a copy of the current medication list.) If you aren't home, how can you be reached? If you can't be reached, who should be called?
- Again, flexibility is key: While you want to clearly communicate expectations and guidelines, you also don't want to be rigid. Give leeway on things that don't really matter. So there was an unwashed pot in the sink, but your loved one is smiling ear to ear from a walk in the park. While safety is not negotiable, almost everything else is. Don't sweat the small stuff. Flexibility!

Once you have successful home care help in place, you now have the opportunity to get out and do some *self-care*—whatever that means for you. Rest, relax, fill yourself up. While no amount of resources will change the fact that this is a difficult, exhausting, often gut-wrenching journey, having help in place to share the caregiving load can make all the difference in how you travel it.

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