

Running Out Of Time, Money, And Independence?

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Abstract

A professor forced into retirement by a severe disability finds his personal care assistants essential. But he may not be able to afford their help much longer—and he faces going on Medicaid and possibly becoming institutionalized.

[Chronic Care](#) [Disability](#) [Multiple Sclerosis](#) [Personal Care Assistant](#) [Long-Term Care](#)

It's 9:28 p.m. Serge punches the code into the digital lock and enters my front door, just as he does every night, seven days a week, asking the same question in his Haitian-accented French about how my day has been: "*Comment était votre journée?*" Serge has a formality that's a bit remote yet friendly: Neither of us seems sure whether to use the formal pronoun *vous* or the more familiar *tu*. He reaches for my phone and pushes the preprogrammed number, accessing his agency's automated time clock and recording his arrival time. Serge's duty hours technically start at 9:30, but he always comes precisely at 9:28.

Serge's arrival interrupts whatever I'm doing—reading a book, listening to music, talking with friends—and I must always be home when he arrives. I resent these constraints and intrusions. This rigid schedule precludes spontaneity or unpredictability in my evening activities. Yet I have no choice: I need his help.

Serge is one of several personal care assistants, or PCAs, who are essential for me to live in my New Jersey home alone despite severe disability. They get me up in the morning and put me to bed at night. They bathe me, dress me, place me on the toilet, clean up my spills, clear away my dirty dishes, bring in and open my mail, do my laundry, and keep my house tidy. Sometimes they cook me meals and feed me. Without Serge and my other personal care assistants, I couldn't live independently, which is what I wish to do.

Serge, Nelita (my personal care assistant in the morning), and their colleagues are among that growing number of "formal" or paid caregivers who provide the most intimate personal services to their clients, allowing me and other people in my situation to remain in our homes. These numbers will expand further as baby boomers age and "informal" care networks of relatives or friends are absent or strained.

The interpersonal demands and dynamics of personal care relationships are challenging enough. Finding people willing to provide these services, ensuring that they are fairly compensated, and paying for these services over the long term are also daunting. Although my experiences with personal care assistants have been largely positive, I worry about the future.

My Life Today

I'm fifty-six years old, and I have primary progressive multiple sclerosis, known as PPMS. The minority variant of multiple sclerosis (it makes up 10 percent of cases), the condition has no treatment, and it causes increasing disability from the moment it starts.

Mine arrived when I was forty-two, and after about eight years, I was unable to move my legs or left arm and retained only partial use of my right arm and hand (I'm left-handed). Today, my trunk and neck muscles are too weak to keep my head erect, so my high-tech power wheelchair must not only move me but also keep my seated body positioned upright and straight.

My arms and legs sometimes move uncontrollably in repeated, spastic motions, causing significant discomfort. I can't control when my bladder empties and, therefore, I have a suprapubic tube. This is an "indwelling" catheter, inserted through my abdominal wall into my bladder, slightly above my pubic bone. It continuously drains my urine into a strong plastic bag that's secured with an elastic strap around my right thigh.

According to the assessment scale that neurologists routinely use to measure multiple sclerosis disability, I qualify as “essentially restricted to bed or chair.” Of the five standard activities of daily living—feeding, bathing, dressing, using the toilet, and walking—used to evaluate disability levels, I can do only one independently: eating. On a bad day, sometimes I can’t even do that. Otherwise, I’m perfectly healthy. Years of long-distance cycling, speed skating, and cross-country skiing made my heart strong.

I’m determined to remain active in my home and community, not to go into a nursing home or assisted living facility. The problem is that I live alone, without the “informal” caregivers—typically wives, mothers, sisters, or daughters, although men are increasingly assuming this role—who provide the majority of personal assistance services to their disabled relatives in the United States. I was born in England and came to America for postdoctoral research after obtaining my physics doctorate from Oxford University. Since then, I’ve lived and worked in Canada and the United States for nearly thirty years, while all my adult relatives remain in Britain.

I could return to England, which offers considerable support for people with disabilities living in communities. In addition to free health care, I would get the maximum disabled living allowance, which isn’t determined on the basis of income. I would be entitled to home health aides, free accessibility modifications to my home, and free stays in respite homes. But there are compelling reasons to remain where I am. Although my marriage ended as my disability progressed, I have two young daughters, whom I cherish. They live a mile away, and I want to be part of their growing up. I want them to visit me in my own home, where I’m living my life as I wish.

After disability stopped me from working at age fifty, I took most of my savings and bought a one-story, ranch-style house. I renovated it extensively, making it as accessible as possible. The accessibility features cost me more than \$150,000 out of pocket. Health insurance doesn’t cover such costs. The limited exception is some Medicaid programs, which occasionally cover purchasing, but not necessarily installing, grab bars and ramps.

The renovations to the house mean that while seated in my wheelchair, I can easily reach my kitchen sink, stove top, refrigerator, storage cabinets, all bathroom fixtures, and other items I might need. I installed an electric lifting device with a ceiling-mounted track leading from my bedroom to the bathroom, which my assistants use to help move me. The exterior doors, side and rear, have ramps. These modifications allow me to get by with relatively little human help; nonetheless, I still need some to meet my needs. My personal care assistants, who come morning and evening, day after day, allow me to live alone in my home. They give me independence.

The Realities Of Finding And Managing Assistants

People use different strategies to find and manage personal care assistants. The “consumer control” approach has people with disabilities independently interviewing and hiring their own assistants, then negotiating and managing schedules and services. Although this approach offers important advantages, vetting candidates and ensuring reliable coverage of essential times are hugely challenging. Personal care assistants are sometimes sick and don’t show up, and some of them occasionally abuse or steal from clients.

I choose instead to use the “agency-directed services” approach. In my case, the agency is a local franchise owned by someone with multiple sclerosis, whom I know. I trust the owner and thus trust the agency to do well by me. The agency performs background checks and hires, schedules, and manages personal care assistants. It continually monitors staff performance. Once the agency had to fire a PCA whom I liked, because she had stolen from another client.

Long-term care insurance from my last job covers the cost of my assistants. At the same time, the dollar amount available limits how much help I can have. My costs are \$1,800 a month, but that amount pays only for three hours of assistant services each day. Personal care assistants earn low wages. Although the agency I use pays more generously than many, it doesn’t give its employees health insurance or other benefits.

Most personal care assistants are women, but some, like Serge, are men. Virtually every assistant I’ve known is either African American or an immigrant, generally

from the Caribbean or Africa. Serge is Haitian and doesn't speak any English; we communicate entirely in French. Personal care assistants have told me distressing stories about how certain clients won't let a black person look after them or treat black assistants in demeaning and disrespectful ways.

Although I no longer work, my days are full. I audit courses at the noted local university. I conduct community accessibility projects for various groups—checking and advocating compliance with the Americans with Disabilities Act for pedestrian crossings, accessibility of parks and mass transit, and so on. I take the train into New York City and Philadelphia to attend concerts and visit museums.

I do the usual errands, too, which always take me extra time to complete. For some of them, such as grocery or other shopping, I take the bus or simply go by wheelchair. I buy some groceries online, but the selection and freshness is better at my local supermarket and farmers' market. I can do most bill paying and banking online, which makes a huge difference because writing is almost impossible for me.

To accomplish all of these activities, I must start my days early. But finding personal care assistants willing to arrive at an early hour is difficult. I've been lucky with Nelita.

Morning: Nelita

Nelita arrives at 6:00 a.m. Her bright smile and cheerful demeanor make the early start easy. Although Haitian like Serge, she has been in this country long enough to have become Americanized, and she prefers speaking English to French. (As with most Haitians, her first language is Haitian Creole; she learned French in school.)

When Nelita arrives, I'm in bed. Even though I can't move my legs or left arm, I can raise the head of my hospital bed with the push of a button, bringing myself almost to a sitting position. To get me out of bed, Nelita places hooks from the ceiling lift device under each of my legs, tucks supports under my armpits on either side of my chest, and then presses the controls to raise me off the bed, transport me along the overhead track, and lower me into my power wheelchair, which has been charging its batteries overnight at an outlet in my bedroom.

This entire procedure takes about two minutes. Once I'm in the power chair, my first stop is the kitchen for a cup of coffee—both to help me wake up and to stimulate muscular contractions in the bowel. The next stop is the toilet.

It's said that people with disabilities seem obsessed with bladder and bowel functioning. But here's my reality: Once Nelita leaves, I'm alone in my wheelchair for the rest of the day, and I can't get in or out of it by myself, even using the lift device. So each morning when Nelita uses the lift to place me on the toilet, I have only one opportunity to move my bowels. After that, I must wait for close to fourteen hours—until evening, when Serge arrives. (The suprapubic tube leading to the leg bag takes care of my urinary incontinence.) This arrangement requires that I be completely in tune with my body, including eating well and healthily.

Not all personal care assistants understand the importance of thoroughly cleaning the anal area after a bowel movement, but Nelita does. Perineal hygiene (cleaning the area between the anus and the scrotum) is especially important, as I remain seated the entire day. So the next step is using the lift to move me from the toilet onto the shower commode chair and into the roll-in shower, where Nelita bathes me head to toe, especially my perineum. Personal care assistants have told me about clients who are too embarrassed to allow a thorough cleaning, especially around their genitals and anus. This cleansing—as well as careful visual inspection of the buttocks—is critical to the prevention and early detection of pressure ulcers or skin infections.

Whenever I can, I still shave my face myself, moving the razor blade down through the shaving cream, leaving my skin feeling clean. Shaving myself is, admittedly, irrational. Nelita sometimes must support my torso while I shave, and occasionally I fail, leaving her to finish the job. But I persist with shaving, mostly because I don't want to give up the last little bit of self-care that I can do.

After thoroughly drying me, Nelita performs her final personal care task: getting me dressed. Most adults never consciously consider their specific dressing preferences—tucking in a shirt this way, adjusting trousers that way. But I can't adjust anything myself. So how Nelita dresses me in the morning is how I'll stay all day. During our time together, she's learned what I like.

Before she leaves, around 7:45, Nelita sometimes helps me get breakfast or does other chores, like laundry or taking out the garbage. After she leaves, I'm alone.

Daytime: Alone With No PCA

No other personal care assistant comes until Serge arrives at 9:28 p.m. Of course, they could: It's only a question of money. But I can't afford more care, so I must make do. Sometimes, when my right arm is too weak to lift a cup or grab a snack bar, I must wait for Serge to arrive to have water or food. I'd be safer with some care during the day, but if something goes seriously wrong, I can count on my personal care assistant agency to provide emergency help.

In a recent week, I had two experiences that underscore these concerns. I'd just heated my dinner—chicken curry with a nice, steaming hot sauce—and was moving the bowl from the stove top to my lap tray. I dropped it. The sauce doused my left hand. Because of spasticity, I can't move my left arm or hand, and the steaming sauce began scalding my flesh. I couldn't put my hand under the cold water in my sink. I tried using my right hand to direct the faucet hose onto my left hand, but I succeeded only in soaking my clothes and wheelchair.

I called 911 with my cell phone, and the police arrived right away, followed by emergency medical technicians (EMTs). I've registered as disabled with local emergency services and given them the digital lock combination for my front door. The EMTs immediately applied an ice pack, stopping the burning, and my left hand appeared relatively unscathed. There was no blistering, and the ice pack eased the pain, so I declined their offer to take me to the hospital. Because I was soaked and the kitchen a mess, I dialed the agency's number. I reached the on-call supervisor, and Serge arrived within thirty minutes and cleaned me up.

A few days later, I positioned my wheelchair seat in maximum tilt, about 45 degrees, which I do periodically to take weight off my buttocks and to prevent pressure ulcers. Coming out of tilt, my wheelchair lost its power. It was dead. Unmovable. With my cell phone, which I always have with me, I called the wheelchair vendor. It doesn't have emergency service, and all it could offer was to send a technician to my home as soon as possible.

I was completely stuck, staring at the ceiling. My laptop computer was a frustrating three inches from my fingertips, and I'd forgotten to place a book in my wheelchair's pouch. Food and water might as well have been miles away. After two hours of sitting, stranded, I called the agency to see if they could send someone over.

Shortly thereafter, the wheelchair technician arrived. The connector of the joystick, located on the right armrest and used to maneuver the wheelchair, had gotten dislodged—something easily fixed. As the technician was doing this, the husband of the agency's owner showed up. He'd been deployed to help me but, fortunately, was no longer needed.

Worries About The Future

I plan to watch my daughters grow up and live many years as adults. But within a few years, I won't have the money to afford personal care assistants. My long-term care insurance will run out in five years or so. Having worked primarily as a university professor, I have only modest savings, most of which I spent to purchase and renovate my home. I easily qualified for Social Security Disability Insurance, as I'm a permanent US resident, and after the obligatory two-year waiting period, I began receiving Medicare. But Medicare doesn't cover personal care assistants.

Through a county-administered program, I qualified to receive disability support from my state, New Jersey, with the stipulation that my assistants be supplied from state-designated agencies. (When my county's Office on Disability Services assessed my personal care assistant needs, it determined I need about twenty-eight hours of help a week. To stretch my funds, I use only twenty-one hours.) But I don't use the designated agencies.

The state pays these agencies only 62 percent of what I pay my private agency, and I don't trust those lower-paid service agencies to be as reliable as the one I use. In addition, personal care assistants from those state-designated agencies wouldn't be free: I'd still need to pay some fraction of the costs. With the agency I use, I know that I won't be stranded, that I won't have to spend the whole day unwashed and undressed. That assurance allows me to live as normal a life as

possible. It's no exaggeration to say that it's the thread that holds me from the slippery slope of self-pity and despair. Nonetheless, I'm a realist, and I know I need to plan for the future.

In contrast to Medicare, Medicaid does cover personal care assistance as a core benefit, and the federal program requires all states to offer it. Yet the actual amount of Medicaid coverage for personal care assistance varies from state to state, and that amount often plummets during periods of recession, as states cut Medicaid costs to balance budgets.

New Jersey is among the less generous states for Medicaid coverage of long-term care services. But it's my only option; I need to be in New Jersey. By putting my house into a trust and making other financial arrangements, I'll be able to become eligible for Medicaid in five years, by the time my long-term health insurance runs out. With New Jersey's current budget crisis, and pending severe funding cuts to services statewide, the status of personal care assistance five years hence is uncertain. Despite that, given my limited financial resources, I'm working to organize Medicaid eligibility.

In the not-too-distant future, having personal care assistants through Medicaid will be the only way I can live in my home. I'll have exhausted my ability to pay for assistants myself. If Medicaid's personal care assistant coverage is inadequate to my needs, I might be forced into an institution, like other people without sufficient resources to pay for assistants.

It's too late for me, but the Community Living Assistance Services and Supports (CLASS) Act, part of the 2010 health care reform, could provide significant long-term care benefits in the future for people in a situation similar to mine. The program will start in 2011, and the secretary of health and human services is expected to set benefits and commence enrollment in October 2012. Enrollees must pay premiums for five years and work for at least three before they can receive benefits, so no benefits will be paid until 2017. On the other hand, there is no lifetime payment limit; nor is there any pre-existing condition exclusion.

Evening: Serge

It's 9:28 p.m., and Serge arrives. Tonight, I don't resent his coming. I've just shopped online for groceries, and a friend brought by some items from the local Asian supermarket. I'm an adventurous cook, but I lack the requisite physical abilities. Serge happily serves as my *sous-chef*, slicing and dicing as we prepare Thai food that will last me for days.

Later on, he'll do much of what Nelita did earlier, but in reverse: emptying urine from my leg bag, getting me undressed, helping me brush my teeth, lifting me out of my wheelchair, and positioning me in bed. Once placed in bed, I can't move until Nelita comes the next morning, so I put this moment off as long as I can.

Before then, we discuss Serge's wife. She was visiting in Haiti on January 12, 2010, when the massive earthquake struck, and she sustained minor injuries. Serge was desperate to bring her back to the United States. Unable to speak English, he couldn't make the necessary inquiries with the airline and organize her flights. This is something that I could do for him.

I was able to get her on a flight from Santo Domingo, and she has now returned to the United States. Serge is grateful for this help. But so am I grateful to Serge and my other personal care assistants. The job they perform—the assistance they provide—allows me to live as normal and fulfilling a life in my own home and community as I can.

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