

NARRATIVE MATTERS



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Remaining At Home With Severe Disability

A person with primary progressive multiple sclerosis manages a complex scheme of personal assistance services to remain living at home.

BY MICHAEL OGG

My life often feels perilously balanced on a knife-edge. I am sixty-four years old and have had primary progressive multiple sclerosis (MS) for twenty-two years—nearly a third of my life. I cannot move any muscle below my neck, and I live alone in a completely accessible home. To support my needs, I require personal assistance services nearly twenty-four hours a day, seven days a week. My health, well-being, and even survival depend on my personal care assistants (my caregivers). The hours I spend each week organizing my services are well worth it, but I've faced significant challenges making this work.

MS is incurable: Nothing could have prevented or slowed my progressive disability. With important exceptions, the major care decisions I've had to make over the years have involved personal assistance services, and each decision has had critical consequences for my quality of life, safety, and ultimately longevity. My story here traces four major epochs of my personal care needs, with each tipping point precipitated by functional declines that gave me no choice but to adapt.

Early Days

It's hard to imagine that many people would like receiving paid help with the

most intimate and intensely personal activities of daily living—bathing, toileting, dressing, feeding, and moving within their home—from, in essence, strangers. As my MS progressed, I adapted my home to maximize my ability to independently perform these activities, with renovations that provided access to my kitchen and bathroom fixtures from my wheelchair, an electric lifting device leading from my bedroom to the bathroom, and ramps for the exterior doors. Nonetheless, in 2005 I finally conceded that without help, I risked injury while showering. So I privately hired a caregiver to assist me each morning, and when she left unexpectedly, I sought caregiver services from a commercial agency.

By then, disability had forced me to retire, but fortunately I had long-term care and long-term disability insurance policies from my last employer. Standard Medicare, my only health insurance, does not cover assistance services except for small amounts in specific circumstances. My caregiver Nelita, originally from Haiti, worked with me through the commercial agency for years, and with those years came more disability. By 2012 I needed considerably more assistance services hours. At this tipping point, my health care proxy Lisa, a health policy researcher with disability expertise (and a fellow wheelchair user), suggested that I consider the Program of All-Inclusive Care for the Elderly, or PACE.

Entering PACE

PACE enrolls people who are ages fifty-five and older and require nursing facility-level care, according to their state's criteria. In New Jersey, where I live, the criteria are related to the number of activities of daily living that can be performed independently. Through supportive services, including adult day care, PACE aims to allow people even with severe disability to remain in their homes and communities, which was my primary goal. PACE receives capitated payments from Medicare and Medicaid, although some states (like mine) permit

people without Medicaid to pay those monthly fees out of pocket. My disability insurance just covered the monthly payments.

I later heard whispers that some interdisciplinary team members of my PACE plan (which here I call “MyPACE”) felt that, especially since I lived alone, I was too disabled for MyPACE and belonged in a nursing home. I declined adult day care, preferring the freedom to conduct my own daytime activities, such as auditing local university and online courses. To my mind, MyPACE amply met my personal assistance needs. Indeed, the program initially authorized twelve hours of assistance services daily, but I asked instead for ten to give me precious private time.

PACE hires, supervises, and manages the caregivers, and my start was somewhat rocky. With the ceiling-mounted lift device in my bedroom and bathroom, I had previously used only one caregiver for my morning showering, toileting, and dressing, but MyPACE insisted on sending two. Eventually I accepted the benefits of having two caregivers, but the schedulers at MyPACE rotated who filled the roles, instead of allowing people familiar with my routines to provide my care. Needing to continually train new caregivers was taxing. Occasionally I asked MyPACE to remove an unreliable or incompetent caregiver. After initial adjustments, MyPACE assistance services largely worked well, supporting my quality of life within my home—albeit not in the community. There MyPACE drew the line: Caregivers could accompany me for medical appointments, but not for activities in the community.

Warning signs did arise. Nurse practice acts in each state regulate tasks that must be performed by registered nurses instead of being delegated to agency-employed home health aides. Although my state had relaxed its regulations, allowing home health aides to administer medications, MyPACE did not yet permit them to do so. My nurse told me that if I needed twice-daily medications, they might have to put me in a nursing home instead of sending the home nurse twice a day. When I developed an excruciating neurogenic pain syndrome that did require twice-daily medication, I engineered a technological solution to avoid the dreaded nursing home. My “Rube



Goldberg” scheme involved clamping a flexible metal gooseneck rod to the kitchen counter and taping a plastic drinking straw at its other end. The daily morning nurse put my evening tablet in the straw tip, so that I could later position my wheelchair in front of the straw and take the tablet in my mouth.

MyPACE No More

MyPACE mostly worked well for over four years, but 2017 brought a cascade of events that unraveled this support. First, I developed a pressure ulcer on my backside that failed to heal. Four weeks later, without consulting me, my doctor arranged to transport me to a nursing home for round-the-clock turning. I did not initially object. However, three weeks later, on her last visit during my nursing home stay, my doctor announced that she did not intend to authorize assistance services for me to return home. She asserted that I was unsafe at home, and against my expressed wishes, she planned to keep me in the nursing home indefinitely. Without assistance services, I could not leave “against medical advice,” as non-disabled people might do.

During the next nearly three months, I grew increasingly despondent, losing hope. With a patient-to-certified nursing assistant ratio of 10 to 1 and my complete quadriplegia, nursing home staff neglected my most basic needs. I was hungry, thirsty, unwashed, unshaven, untoileted, and despairing. I lost all dignity and self-respect, except when Nelita, who now worked for me through MyPACE, washed my hair and gave me a

shave. In the end, I left the nursing home only because they so badly mismanaged a weeklong febrile illness that I became badly dehydrated, risking acute kidney problems. They transferred me to a hospital, which found that my initial pressure ulcer had healed—though I now had multiple new pressure ulcers and extensive maceration on my backside.

I was resolved: I would not return to the nursing home. But my doctor would not authorize assistance services. She contravened my most basic right, my “dignity of risk”—my right to make decisions about my own care, understanding well the risks and benefits of living at home. If I was to return home, my only choice at the time was to leave MyPACE and organize my own assistance services.

(Of note, Lisa had connected me with disability legal aid services that appealed to the Centers for Medicare and Medicaid Services adjudicator MyPACE’s decision to deny assistance services. I won what became two appeals, and MyPACE was ordered to reauthorize my assistance services. However, the final decision came three months after I had left the program.)

Self-Managing Personal Assistance Services

During my time in the hospital, Lisa, despite living several states away, made increasingly frantic phone calls trying to arrange assistance services for my return home. She at last found a willing doctor and home visiting nurse agency, but organizing caregiver coverage was more challenging. I reconnected with my commercial caregiver agency from several years previously, which welcomed me back. My joy at returning home in late October 2017 was tempered by a new reality: I had not anticipated the many hours and complications of managing my assistance services.

The caregivers provided through the agency were typically low-wage workers—often immigrants and not native English speakers. I have extensive needs, beyond those of most agency clients, and needing to communicate minute-by-minute with staff with low English proficiency was frustrating. Though I have installed technologies to facilitate my care, operating these de-

Policy Checklist

The issue: Personal assistance services allow many people with serious illness or disability to remain at home rather than in institutional settings such as nursing homes, but high costs, practice restrictions, and caregiver challenges make such care complex to manage and maintain.

Related reading:

Long-Term Services and Supports State Scorecard (AARP). "Promising Practices," 2018, <http://www.longtermscorecard.org/promising-practices>

National Association of Insurance Commissioners, Center for Insurance Policy and Research. "The State of Long-Term Care Insurance: The Market, Its Challenges, and Future Innovations," May 2016, https://www.naic.org/documents/cipr_current_study_160519_ltc_insurance.pdf

D. Redfoot, W. Fox-Grage (AARP). "Medicaid: A Program of Last Resort for People Who Need Long-Term Services and Supports," May 2013, https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2013/medicaid-last-resort-insight-AARP-ppi-health.pdf

VICES requires training. In addition, my MS-related spasticity causes unexpected, powerful limb movements that my caregivers must manage while operating the devices. By 2017 my long-term care insurance had long since run out, but I continued the practice of having two caregivers perform my morning routines, despite the added cost. With frequent turnover of agency caregivers, repeatedly training new workers became time-consuming and exhausting. Within a few minutes of meeting them, I could tell whether new caregivers would be adept and willing to learn.

Lisa suggested trying consumer-directed assistance services, in which I would hire and manage my own small staff of dedicated workers. I did retain one consumer-directed caregiver: Nelita, my long-time aide. But I quickly realized that organizing all of the hundred hours of the weekly assistance services I needed would be too challenging. Relying on the agency, despite the frequent turnover, had important benefits, including their screening of caregivers, managing the payroll, and supplying backup staff. Plus, because I received home nursing through Medicare, I was entitled to two caregiver hours Monday through Friday, ostensibly to assist the nurse.

During this period, I had a complicated mix of personal assistance service workers covering my needs roughly fourteen hours per day. Although I

needed all of those hours, the reality of the new expense hit me hard every time I reviewed my bank statements. My out-of-pocket expenses were now outstripping what I had previously paid MyPACE.

Another Tipping Point

MS takes its own course, and in July 2018 I finally acknowledged that my functional status had reached yet another tipping point: I could no longer swallow pills or eat safely and efficiently. I frequently regurgitated medications, and eating my meals was a long and exhausting process. Plus, nearly a year after I had left the nursing home, the skin over my pressure ulcers remained fragile, painful, and susceptible to reopening, keeping me largely bedbound. Having caregivers there fourteen hours a day allowed frequent turning to off-load pressure and help healing, but I felt that little progress was being made. My neurologist worried that the swallowing difficulties had compromised my dietary intake: Good nutrition is essential for wound healing.

On my sixty-fourth birthday, my neurologist admitted me to her academic medical center, where several specialists recommended a feeding tube. Enjoying good food, I had always dreaded that, but I had no choice, and the feeding tube was surgically placed. I would receive feeds directly into my stomach: bags of

pale yellow nutrients specifically meeting my nutritional needs from a tube snaking through a pump attached to an IV pole. I spent several weeks in the hospital and in rehab finding a good equilibrium of feed quantity and pump speed, settling on three daily one-hour feeds. It is an odd sensation never feeling hungry but also never satiated, and during those weeks, I lost all sense of taste.

The feeding tube forced a fundamental reorientation of my complex but quasi-stable personal assistance services scheme, which relied heavily on staff from the commercial agency. Nurse practice act restrictions prevented the home care aides from administering tube feeds. The agency nurse could do it at \$75 per hour—which was clearly not financially tenable. My only option was consumer direction: hiring and training my own private caregivers, who are not governed by nurse practice act restrictions.

Consumer Direction

Because of my feeding tube, the rehab hospital would not discharge me home without assistance services in place. Hospital social workers do not make these arrangements. I couldn't either from my hospital bed, nor could Lisa from 250 miles away. I needed local help to organize consumer-directed assistance services. Fortunately, I found this assistance in a woman named Debbie, whom I met through my community-based social network.

Debbie, Lisa, and I composed a brief job description, and Debbie advertised online, screened candidates' résumés, and conducted initial interviews. In my area, agencies pay home health aides an average of about \$12 an hour, although the agencies charge consumers much more. Private-pay caregivers earn up to twice what an agency pays. I needed to meet final candidates before hiring anyone, but I couldn't do so until I returned home. I could cover other needs through the agency, but for discharge, I still required someone to perform tube feeds. Here luck intervened: Nelita's son had just received his nursing degree and was about to take the state's licensure exam. He agreed to temporarily administer the tube feedings, with supplies

organized by the home nursing agency and covered by Medicare. With these services in place, the rehab hospital discharged me.

For the second time in under twelve months, I returned home to new realities. I would now hire my own caregivers, whom I would oversee. They would provide not only standard support but also tube feeds, medication administration, topical pressure ulcer treatments, and other tasks.

Debbie had identified two excellent candidates for my consumer-directed caregivers, whom I met the day after returning home. I agreed with Debbie's positive assessments of Rita and Twana, and they started working almost immediately. I also decided to hire an agency caregiver to assist Twana with my morning routine.

Although Rita and Twana initially covered me daily, including weekends, I worried about burnout. Debbie and I started recruiting someone for weekend coverage, but here I was lucky again. Nicole, the sister of one of my agency caregivers, was working as a phlebotomist but needed another job to make ends meet. Across the dozens of caregivers I've known, many, like Nicole, worked two or even three jobs to earn sufficient income. As the final piece in the puzzle, my long-time stalwart Nelita covers five evenings a week as her third job.

As I write this, six months have passed since I returned home from the hospital. I have four consumer-directed caregivers, and I receive three hours of care each morning from agency personnel. This arrangement generally works well, but it's quite an operation for me. It's like running a small business where I am both the manager and customer. Debbie sometimes takes the human resources manager role when I need administrative help or guidance, such as with tax forms for my aides. It takes at least five hours of my time per week, but without my assistance services, I would not have the dignity and quality of life that I want. My assistance services are costly, too, consuming all of my monthly fixed in-

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come and draining my modest savings. I know that affording these essential services is untenable in the long term.

Out Of Options

So now I find myself on the precipice of another tipping point. Unlike the others, which were caused by my progressive disability, this one is purely financial. Unlike many Americans, I had recognized that Medicare does not cover personal assistance services, and I had planned ahead for this contingency, playing by what I thought were the rules. I was one of the 5 percent of Americans ages 45–64 who, according to the Center for Insurance Policy and Research, have long-term care insurance, but that coverage ran out long ago. I had a good long-term disability policy, but my last check will arrive shortly. I am careening down that sluice of final resort: I am arranging my assets (the so-called spend down) so I can obtain Medicaid and with it essential personal assistance coverage, which I need to live. My life is about to change irrevocably, and I am afraid.

This is what preparing for Medicaid looks like for me: I have spent the past six months constructing a complicated edifice of consumer-directed personal assistance services, which is not always elegant but has allowed me to remain at home despite 24/7 needs. Doing so has required me to pay my home health aides higher hourly wages than I understand New Jersey Medicaid allows, and I therefore anticipate that my home care edifice may come crashing down. I cannot live without that intensive support,

yet I have no idea what will take its place.

In addition, my PACE experiences haunt me still. With my former doctor and senior officials from my PACE program keeping me involuntarily in a nursing home, I had no control over my own health and welfare decisions. The notion of safety is a fallacy: The conventional wisdom is that a nursing home is a safe environment, but my experience clearly shows otherwise. The principle of dignity of risk is that I have the legal right to make my own decisions. Furthermore, as the US Supreme Court ruled in *Olmstead v. L.C.* in 1999, I have the civil right, under Title II of the Americans with Disabilities Act of 1990, to live in the community, if I wish—and that is my wish. But will Medicaid respect that right?

Finally, I recognize the financial restrictions that are about to be imposed upon me, including the limited monetary allowance and the fact that New Jersey will recover assets from my small estate (basically, my home) to recoup the dollars spent on my care. I have lived frugally, anticipating this time, but having my monthly expenditures so constrained will take some getting used to. That is not, however, what is keeping me awake at night lately, causing my undercurrent of dread. My concern is whether the Medicaid authorities will respect the values that I live by, and the fact that—despite my disability—I want to go on living on my terms, in my own home. Will I still have control over how I live my life? ■

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