

# *Preface*

My mother typically dozed off early and was wide awake at 4 a.m. or earlier. Parkinson's and congestive heart failure had made her exceedingly frail, and she was exhibiting signs of dementia. The Medicaid-authorized aide did not arrive at my mother's tiny apartment in the senior facility until 9 a.m. for her eight-hour stint, the maximum available.

I got the Medi-alert agency calls in the wee hours, and my wife and I stayed with her at the ER for as many as 18 hours. There were five falls that year, yielding one hip replacement and three 30-day rehab stays in a nursing home.

Intense anxiety and tedium accompanied the hours my wife and I spent waiting in the ER or at my mother's home, giving me a glimpse of how such caregiving might lead to depression. I was trapped in a role I didn't want. My mother didn't want me in the role either, and kept telling me to go home. The nursing home rehab stays were intolerable for her. She would sit in her wheelchair in the hall near the nurse's

station for hours, despite serious back pain. My wife and I felt the need to visit daily and advocate for her needs.

Most approaches to preventing or ameliorating caregiver burden are reactive. They take the family caregiver role as a given and suggest moderating burden through adult daycare, respite services, counseling, and social support networks. While certainly useful, these approaches have only a limited impact and will certainly not be available to the extent needed over the next three decades.

A proactive approach would aim to diminish the family caregiver role. This is where personal care aides come in, particularly those deployed round-the-clock in the client's home. In addition to dealing with the usual activities of daily living, they prevent falls, manage sleep-cycle problems, assure medication compliance, and handle tasks set by visiting nurses. They also prepare favored foods, tune in favored TV shows, get clients out for fresh air, and prepare for family visitors. A personal care aide can be far more attentive than can an overworked nurse aide in a nursing home. They can also respond quickly to client discomfort or need, avoiding the frustrating and depressing wait times typical of nursing homes.

There are many issues to be addressed in expanding the use of round-the-clock in-home aides, especially the turnover associated with the job's poor pay and training. Better compensation and meaningful benefits will reduce turnover and attract more workers to the field. Aides

must become valued paraprofessionals and an important part of case management.

My mother's geriatrician filled out forms indicating she needed a 24-hour personal care aide to help with activities of daily living. The New York City Medicaid program is one of the most generous in the nation and authorizes 24-hour care if the client is medically stable and he or she (or a nearby family member or friend) is able to direct care. New York wants to keep older adults out of nursing homes, believing it best for the client and expecting it to be cost-effective in the long run.

The agency aides we saw were poorly paid, minimally trained, and sometimes semi-literate, but we were lucky to eventually get a wonderful woman who worked five days a week (a second aide came for the other two) for years. She understood the idiosyncratic needs of a cranky, incontinent, and increasingly demented elder. My mother lived out her life comfortably, in her apartment. My wife and I managed her affairs and visited regularly. We were deeply relieved.