

## WHAT'S CRAZY ABOUT LIVING WITH DEMENTIA?

By Michael Fine

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Basically, everything is crazy, for the caretakers of people living with dementia. If you have dementia, it's hard for you, because you can sense what you don't know or understand, and sometimes see the apprehension and disappointment in the eyes of the people you love, and feel that but too often don't understand it, which is part of the cruelty of dementia itself.

But as hard as dementia is for the person who is living through it, it is even harder for the person's caregivers. Those caregivers live in a vortex of losses – they have lost the intimacy of their experience of their loved one's personality, while living every day with the memory of that intimacy; they have lost their freedom to have their own life; they have lost their sense of physical security, because they always must be on the lookout for their loved one's safety; and they often sustain significant financial losses as well, because assisted living and nursing home care is so egregiously expensive.

I have two sets of friends who are going through this. It hurts to see and hear about what they are going through.

The good news is that there are some options for people living with dementia. The bad news is that most of those options are too damn expensive.

PACE, the Program of All Inclusive Care for the Elderly, is a great non-profit organization that is often the best option for people who are frail but don't yet need nursing home care. PACE does all the medical care and medications for the frail elderly, people who are likely to need nursing home care but can still be in their own homes with enough support. PACE provides day centers and transportation vans to help people get to appointments and to the day centers, and has an exquisite team of nurses, social workers, doctors, CNAs, nurse-practitioners, physical and occupational therapists and others – a great team, which has the right people to help frail elderly folks stay at home as long as possible. (Disclosure – my wife works for PACE as a physician part-time.)

PACE is really for people with both Medicare and Medicaid, a population that is usually disabled and low income. But what's crazy is that few middle income or wealthy people know about it and use it, even though it provides the best care imaginable. (It is also amazingly effective at

keeping frail elderly people at home, often for years longer than they'd be able to manage for themselves, which is why Medicare and Medicaid supports PACE.)

But anyone can actually use PACE, although it doesn't come cheap. It costs about \$4000 a month, if you have Medicare and must pay for the piece not covered by Medicare yourself. So about \$50,000 a year. Wow! But still less than half the price of nursing home care, if that's the alternative. For most people, fortunately or unfortunately, that cost continues a few years but not forever, because most people who use PACE are towards the end of their natural lives.

So the good news is that there is a great option for people with dementia and the frail elderly. The bad news is that there are many people, who aren't poor but aren't rich and who might benefit from PACE, but can never see themselves affording it.

But think with me about health care in a different way, for a moment. Imagine a health care system, where there were a hundred health centers in Rhode Island, one in every neighborhood and community. Imagine that each health center had a team of health professionals like the team at PACE -- nurses, CNAs, community health workers, social workers, physicians and nurse practitioners or PAs, physical and occupational therapists, pharmacists and others, who were charged with the responsibility of caring for everyone in that neighborhood or community.

Could those imagined health centers do what PACE does? Probably. There might only be thirty or forty frail elders or people living with dementia in each community, if you run the numbers and spread the number of frail elders over the state as a whole. Most of the health center's time would be devoted to people who were not that frail, but the team would be there for the frail elderly as well. Would that kind of care still cost \$50,000 a year? Nope. It would be part of the fixed overhead of running the health center, which could care for the frail elderly and serve its community as well. A smart approach would be to make PACE level-of-care free, so we could support the frail elderly in their homes as long as possible *and* keep families and communities intact. And likely save millions of dollars by doing so, if you multiply the \$50,000 a year savings over nursing homes by three thousand, so a savings of something like \$150 million a year, to be precise.

You see, most health care is actually affordable, when you spread its costs over all the people who live in a community.

But that's not what we do. We've turned health care into a commodity, with slivers of services that can be bought and sold like tomatoes or TV sets. Which allows the sellers to make big money, but this process jacks up prices, and so makes lots of health care unaffordable, as the money we spend on health care goes to profit instead of caring for communities and the people who live in those communities.

Is that crazy? You tell me.

