When our parents become old and infirm — and then we ourselves — where do we turn?

We first think of our Medicare and/or Medicaid coverage. These can buy us access into doctor’s offices, emergency departments, hospital wards, intensive care units, and other covered services. If we live through an acute situation — the heart attack, the stroke, the cancer, the fall and broken hip, the bout of COVID pneumonia — Medicare and Medicaid will cover Mom or Dad for a short stint. But if you’re facing a prolonged stay in a rehabilitation hospital or a skilled nursing unit. Medicaid (not Medicare) is funded mostly by each state (with a minor amount coming from the federal government), and there are significant rule and reimbursement variations among them.

But here I am specifically talking about after the acute illness, after the covered days. I am talking about the rest of your aging, infirm, frail loved one’s time on this earth. Those months and years — who knows how long? — are when your now dependent elder will require increasing assistance with some or all of the activities of daily living we take for granted: eating, grooming, dressing, bathing, toileting, transferring from bed to chair, and ambulating.

Yes, your 85-year-old parent with mild dementia may get “back on his feet” briefly after a hospital stay for heart failure. Or your spry 90-year-old mother may survive surgery for her fractured hip and go home with a walker. But if you believe that “everything is just fine now,” that they can continue to stumble along in their lives as before, either you are facing this scenario for the first time or you are deluding yourself.

Perhaps, in the back of your mind, you are thinking, “Well, there’s always a nursing home...” Let’s consider that for a moment. Under our current system, it is Medicaid that covers long-term custodial nursing home care. States with poor Medicaid funding streams (Texas among them) tend to have fewer desirable nursing home environments and care. In Texas in the year 2022, a couple’s before-tax annual income must be less than $36,254 to be eligible for Medicaid. And even if this applies to your loved one, there are other hoops to jump through — such as an accounting of other assets, including (in Texas, at least) the family home.

Should you still be eligible for Medicaid, depending on where you live, perhaps a Medicaid-funded bed can be found in a custodial nursing home. Perhaps it will be better than average, and you will be satisfied there. Too often that is not the case.

In America, you get what you pay for. Sadly, for our aging citizenry it has always been thus. The median balance in the retirement accounts of individuals 75 years or older in America today is $83,000. (The “median balance” means that half of us have more than this amount, and half of us have less.) In 2022, the average per diem private nursing home room cost in Texas (San Antonio Region) is $228, or $83,320 per year (“Nursing Home Costs by State and Region,” American Council on Aging, updated March 4, 2022, https://bit.ly/3PK82ux). This figure can be much higher in other states. Simple arithmetic will tell you how many months your loved one can afford to stay in a long-term care facility paid out of personal retirement savings. It is too often the case that these financial assets will be depleted long before the individual’s remaining life span.

In her thoughtful and well-researched book, MediCaring Communities: Getting What We Want and Need in Frail Old Age at an Affordable Cost (2016; available online at https://medicaring.org/book-online/), the geriatrician and director of the Center for Elder Care and Advanced Illness at Alpert Institute, Joanne Lynn, MD, lays out the problem before us: “Frail elders were rare in 1965 when Medicare started. Using age as a marker for frailty, the number of people 85 years old and older in the U.S. in 1960 was just under 1 million. By 2000, we had 4.2 million. By 2050, we’ll have 18 million.”

Dr. Lynn describes the problems of overhospitalization due to the lack of home-based care, inappropriate medications and treatments, and a culture that doesn’t recognize the unique needs of older adults. Her book outlines what Dr. Lynn labels the “Core Components of a MediCaring Community.” These include:

• Frail elders identified in a geographic community
• Longitudinal, comprehensive, and personalized elder-driven care plans
• Medical care tailored to frail elders
• Scope to include social and supportive services
• Monitoring and improvement by a community board
• Financing with savings from Medicare

The key concept here — and the current obstacle — is that to get these “MediCaring Communities” off the ground and running will require the use of federal and/or state dollars. It is not likely that our government, as currently connected and politically divided, will ever propose — let alone pass and fund — additional legislation that will underwrite the long-term services and supports that are essential to humanly maintain our elder population as we become more frail yet want to live on independently in our own homes. Dr. Lynn enumerates what will be needed (in section 4.1):

• Care coordination/case management/navigation
• Personal care (baths, toenail cutting, hairdressing, bed changing)
• Homemaker services (cleaning cooking)
• Home hospice
• Adult day care and day hospital services
• Home-delivered meals or food
• Meals at congregate sites
• Home reconfiguration or renovation (ramps, lighting, grab bars, toilets)
• Caregiver skills education, group support, respite
• Medication management (loading pill dispensers, ensuring access to medications)
• Skilled nursing (wound care, handling special medications or devices)
• Telephone reassurance and monitoring services
• Technologies that promote connectivity
• Emergency and urgent advice and help for non-medical issues
• Equipment rental and exchange
• Adapted transportation, door to door
• Legal and financial help
• Investigation of potential abuse, fraud, or neglect
• Counseling to improve family dynamics
• Friendly visitors and telephone networks for socialization
• Socialization (calling networks, neighborly check-ins, group activities)

If you study this list and shrug, saying to yourself, “Well, this seems overly comprehensive,” you have never been a caregiver for any length of time. But if you shed a few tears — or many tears, or even fly into a rage — it is because you remember all that you had to do, arrange, accomplish, fix, assuage, explain, worry over, and learn about, all without guidance or help or assistance. Or all the money (perhaps every dime of savings you had) that your family spent on caregivers or aides or nursing homes, yet you could still never seem to get it right, to get what you needed for someone you loved when you needed it.

If you’ve followed my columns in Caring for the Ages these last twelve years, you will understand that I, myself a doctor of the oldest old, often felt overwhelmed caring for my parents in their home: a father with dementia and a mother with multiple chronic medical problems. We were always waiting for the next acute event: the delirium, the stroke, the fall, the cellulitis, the pneumonia. At times, I despaired — even me, someone with the knowledge and wherewithal most do not possess. I had promised my parents I would keep them out of the hospital once the end was nearing, that they would die in their own beds. I know many of us would like to manage this as well, if we just had the support systems to make it happen.

And this is what Dr. Lynn’s vision of MediCaring Communities is all about. As she defines them, “MediCaring Communities are organized and tailored to meet the needs of frail elders. ... The foundation ... rests on comprehensive assessment and creation of individualized care plans that reflect the older person’s strengths, needs, and goals, as well as a locally-anchored service delivery system that is monitored and manageable to ensure that what individuals in the community need most is available.”

Models like this already exist in some communities in America. PACE (Programs of All-Inclusive Care for the Elderly Beneficiary) is one such government program available to folks on both Medicare and Medicaid that provides in-home services such as adult day care, dentistry, home care, meals, nutritional counseling, and social work services in addition to primary and hospital care. An interdisciplinary team, consisting of professional and paraprofessional staff, assesses an enrollee’s needs, develops care plans, and delivers all services (including acute care services and, when necessary, nursing facility services). The team meets regularly to discuss the patients in their charge and review their status. PACE programs have demonstrated reductions in in-hospital days, emergency department usage, and need for hospital readmission. In addition, fewer long-term care placements and reduced rates of functional decline and mortality have been documented in populations of PACE enrollees (S. Karon et al., “Expanding the PACE Model of Care to High-Need, High-Cost Populations,”

Continued to next page
And there are many other examples such as these that Dr. Lynn discusses in her book. The money comes from rejigging how Medicare allocates payments to providers. America spends more money by far on medical care than any other modern Western democracy (19% of our gross domestic product [GDP] in 2020). The United Kingdom, for example, spent 13% of their GDP that same year. Before the COVID-19 pandemic, the British National Health Service (NHS) had high patient satisfaction in their over-65 population (68% in 2019) despite the fact that they spend so much less per capita on medical care. Perhaps this is because the NHS spends half again as much as we do on “social care” (J. Appleby et al., “Public Satisfaction With the NHS and Social Care in 2019: Results from the British Social Attitudes Survey,” Nuffield Trust/The King’s Fund, 2020, https://bit.ly/3Ajfe3F).

Now, with the pandemic, these patient satisfaction scores have fallen off significantly across all age groups although “support for the principles of the NHS remains strong, with 94% believing the NHS should remain free of charge ... and 83% agreeing the service should be available to everyone” (J. Plewes, “What the Latest Data Tells Us About Public Satisfaction With the NHS,” NHS Confederation, March 31, 2022, https://bit.ly/3QM8TLE). Hopefully, after the strain of the pandemic has passed, these satisfaction scores will bounce back to baseline.

With a reduction in what we waste on unnecessary, often dangerous medical care for our oldest patients while increasing our spending on what our frail elders need in their local communities like the NHS does, financing ambitious plans like MediCaring on a large scale would become possible. Our frail elders need help, and Americans need jobs. What we all need is a visionary plan and a will to overturn the status quo.

Some states are beginning to fund support for folks to remain at home. Many families would just as soon care for their loved ones at home, and think of the cost savings to society at large: even though my home state of Texas ranks 49th in the nation in its reimbursement rate to nursing homes, it could still save billions by shifting some of its Medicaid resources to home care. Some states — even mine — are paying some family caregivers to provide in-home care to a loved one.

As Americans, we must continue to experiment and evolve new models of long-term elder care. If we dither and bicker and allow the giant profit-making entities of America’s medical-industrial complex — Big Insurance, Big Pharma, and corporate hospitals and long-term care institutions — to drive the conversation on how best to care for our burgeoning elderly relatives and friends ... well, you yourself, currently ensconced in your busy workaday life as breadwinner, partner, or parent, might never be able to attain your own secure, affordable, and peaceful old age.

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