Healthcare’s Invisible Workforce:
Honoring and Supporting Family Caregivers during National Family Caregiver Month
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This blog is adapted from an OpEd written by Jennifer Raymond, Vice Chair of the Evidence-Based Leadership Collaborative and Karen Voci, President of the Harvard Pilgrim Health Care Foundation (First appeared on CapeCodToday.com)

The signs, those unmistakable symptoms of progressive dementia, started slowly, albeit in textbook fashion for Natalie’s mom. At first, it was just forgetfulness, even about things that occurred only moments ago. Then her mom started calling at strange times, repeating the same stories. She often appeared confused for no apparent reason.

Natalie felt fortunate that she lived within an hour of her parents’ home; she had envisioned calling on them to help care for her 18-month-old little boy. Now the tables had turned and a future she thought would be filled with play dates, school plays and family vacations was clouded by the looming need to tend to her aging parents.

She kept her fears to herself until she attended an evidence-based Savvy Caregiver workshop offered by Elder Services of the Merrimack Valley, through its Healthy Living Center of Excellence. There, surrounded by people in similar situations, Natalie heard herself for the first time admit out loud that her mother was showing signs of dementia. It was an emotional turning point but more importantly, it was an eye-opening revelation about the support and services available for those with adult family members and friends coping with chronic illnesses or conditions that prevent them from handling daily activities such as bathing, managing medications or preparing meals on their own.

Long-term care, assisted living and outside caregivers are expensive but thankfully, not the only options available. As Natalie discovered, daughters, wives, husbands, sons, grandchildren, nieces, nephews, partners and friends all serve as caregivers. Research confirms what we have long believed: while some people receive services from paid caregivers, most rely on unpaid assistance from families, friends and neighbors. According to the Family Caregiver Alliance, about 44 million Americans dedicate 37 billion
hours of unpaid, "informal" care each year for adult family members and friends. Family care eliminates the need for more expensive residential services and unnecessary hospital admissions while keeping friends and family members in a familiar environment. The estimated economic value of family caregivers' unpaid contributions is approximately $470 billion, which is how much it would cost to replace that personal care with paid services.

With dementia reaching epidemic proportions, innovative programs must be part of the nationwide movement to keep older adults at home. It’s necessary that caregivers receive the proper tools, skills, techniques, strategies and support they need. In Natalie’s community and in others around the region, family caregivers can get help and encouragement from evidence-based programs. These programs can teach caregivers important information such as the stages of certain diseases and the effects on patients, as well as the available resources and networks in their communities. Programs like Savvy Caregiver, Powerful Tools for Caregivers, Building Better Caregivers, and many others also help instill more confidence in making decisions and providing structure and support, as well as help participants learn greater patience and resilience.

With the need for support and essential services for dementia patients growing at a rapid rate, programs like evidence-based caregiver programs help families deal with the heavy demands of caring for ailing friends and family members while driving down healthcare costs for all. While the caregiver training that Natalie received was free, the program doesn’t come without costs. This vital work is supported by grants from the Harvard Pilgrim Health Care Foundation and other wellness advocacy groups.

We urge community-based organizations across the country—especially those working on the front-lines to offer healing, help and hope to families coping with the complex demands dementia patients—to consider adopting these evidence-based, low-cost, high-touch programs which provides much-needed guidance, resources and support for caregivers.