

## **Policy and family together — who will take care of elderly family members?**

BY MARGARET DANILOVICH (The Hill, 12/23/16)

Sooner rather than later is always best; and prepared is better than not.

As people age, the likelihood of hospitalization, falls and memory impairment increase forcing older adults and their families to make immediate caregiving decisions.

As a physical therapist with 10 years of experience working with older adults, I have witnessed the difficult caregiving decisions families make in the wake of healthcare crises. Without a plan in place, the urgency becomes who will take care of this loved one? And is this the best choice?

When my 79-year-old patient had a stroke, his family struggled determining how he would receive care. His daughters were overwhelmed with his extensive needs. They grew resentful over the differences in time and financial support. The family discord frustrated my patient. He eventually chose to enter a nursing home to not burden his children.

Further complicating matters is that family members are rarely trained to perform critical caregiving tasks such as administering medications, managing oxygen and catheters, and assisting with using the bathroom, walking, and feeding.

Almost 60 percent of caregivers assist with medical or nursing tasks such as continence management and medication administration. Only 14 percent report they are trained to do so. This contributes to unsafe and stressful environments that are potentially harmful for both the older adult and the caregiver.

To address this gap, the Caregiver Advise, Record, Enable (CARE) Act requires hospitals to educate and instruct caregivers in medical tasks prior to discharge. Ohio became the 35th state recently where this is law. This legislation is pending in Texas, California, New Jersey, Oklahoma, and New York to support caregivers of hospitalized adults. It needs to be in place in every state.

But we also need policies that provide education and training to the 34.2 million caregivers of older adults residing in the community. President-elect Donald Trump has made little to no mention of his plans for supporting caregivers. As president of a country with a rapidly aging population, specific policies need to be a focus of the incoming administration.

To minimize problems of caring for an older family member, the solution is to identify the caregiving arrangement prior to an urgent health issue.

The answer could be a family member, a paid/formal caregiver, adult day services or a combination of care options. The critical plan includes families discussing — hopefully far in advance — who would assume primary caregiving responsibilities. Then the identified caregiver has a choice to accept or decline these responsibilities.

More than 50 percent of caregivers have no choice in becoming a caregiver and this lack of choice contributes to stress, physical strain, and poor health outcomes for the caregiver.

Our research team at Northwestern University analyzed data from the recent Caregiving In The U.S. survey and found that having a choice in assuming care for an older adult family member produces a four times greater likelihood of self-reporting improved health. Improved self-reported health is associated with less healthcare utilization, reduced mortality risk, and improved physical functioning.

Older adults may suffer from anxiety and uncertainty when there is no pre-determined caregiving plan. When medical crises strike, older adults are less able to voice their caregiving preferences, limiting the ability to receive care from preferred persons and in the setting of choice such as one's own home, with a relative, or in a nursing facility.

Family members need to have conversations about who, when, and where the person will receive care before a health change. That way all family members have a voice in the caregiving plan to foster participation and share care responsibilities.

Certainly, social pressures cause people to feel obligated to become a family caregiver. We need to eliminate the stigma around choosing not to be a primary caregiver. It is stressful to shoulder day-to-day responsibilities of caregiving. Not everyone has the capacity, ability or desire to perform these tasks.

Financial concerns also influence the decision. Talking in advance about preferred caregiving arrangements will help families better organize finances to support expenses. Female caregivers lose on average \$50,000 more than men do in lifetime lost wages due to the impact of caregiving.

Greater public funding for affordable and accessible formal caregiving services will assist those caregivers who must assume caregiving responsibilities, as well as support older adults for whom family caregiving is not an option.

Older adults can receive formal caregiving services through Medicaid, but this policy only applies to low-income older adults. Middle class individuals often have to "spend down" their assets to qualify for these services or pay up to \$50,000 per year out of pocket for care.

Yes, family dynamics influence caregiving decisions. Policymakers cannot intervene on these long-standing relationships. But they can support the choices with effective, beneficial policies.

What we can do individually is create a plan for the care of older family members, perhaps as part of this year's New Year's resolutions.

What we can do as a society is provide resources to those who feel an obligation to become a caregiver.

In a country projected to add 250,000 older adults to its population each month for the next 13 years, a public health crisis will occur if appropriate caregiving plans and supports are not enacted now to provide for an aging population and its caregivers.

Better late than never.

See also:

Caregiving in the USA:

[http://www.caregiving.org/wp-content/uploads/2015/05/2015\\_CaregivingintheUS\\_Final-Report-June-4\\_WEB.pdf](http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf)