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The growing burdens of CAREGIVING

By Melissa Weidman



Joan Konopka took care of her husband Bruce for three years, grateful to be able to keep him comfortable at home until the end. For much of that time, they received services from Hope Hospice. Even as a certified nurse receiving hospice care, she was surprised by the full scope of that challenge. "Even with all my expertise, I was overwhelmed.

It felt like I was all alone in this struggle," she said. A research report recently released by the AARP Public Policy Institute in conjunction with the National Alliance for Caregiving shows she is far from alone in this kind of experience.

T i t l e d "Caregiving in the United States," the report summarizes survey findings from interviews conducted with 1,248 caregivers aged 18 and older who provide unpaid care to an adult. The survey defines caregivers as "helping with personal needs or household chores ... managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This

adult need not live with you."

The report's key findings demonstrate approximately 34.2 million unpaid caregivers in the United States caring for someone age 50 or over. The majority are female. Their average age is 49 years old, with most caring for a relative, frequently a parent or parent-in-law. They come from every age, gender, socioeconomic and ethnic group.

The report states, "When caregivers are asked what they perceive to be the main reason their recipient needs care, the top three problems reported are old age (14 percent), Alzheimer's or dementia (8 percent) or surgery/wounds (8 percent). More than half of care recipients have been hospitalized in the past 12 months (53 percent)."

The survey shows those who spend the most time caregiving per week (more than 41 hours) experience the highest stress and receive the least support. They have been providing care for an average of five years. They are more likely to have difficulty performing the medical and nursing tasks required, and have little to no training or preparation in doing so. They report high levels of emotional stress, physical and financial strain, and their own poor health worsened by the responsibilities of caregiving. Caregivers often experience limitations in fulfilling their regular jobs. Half of all surveyed said they had no choice in taking on their role. Konopka says, "I woke up every morning thinking about what he needed. It wasn't until I fell asleep at night that it even crossed my mind that I had needs as well. And then it was too late to even think about that."

The daily burden of getting loved ones showered, toileted, dressed, medicated and fed are only part of the picture. Caregivers must also advocate on their loved one's behalf with health care providers, deal with financial issues,

cook, clean and maintain the household. Medical tasks include giving medicines, preparing food for special diets, tube feedings or wound care. They monitor blood pressure or blood sugar, help with incontinence, or operate equipment like hospital beds, wheelchairs or oxygen tanks. No wonder it's such an overwhelming challenge.

"As my husband's condition declined, my responsibilities multiplied. It felt like having a baby again, when you first bring it home and have no idea what to do," says Konopka.

According to the study, only a third of caregivers say a health care provider had asked them about what they needed to care for their recipient. And 16 percent say a health care provider never asked what they needed to take care of themselves. More than 80 percent stated they could use more information on caregiving topics such as safety and stress management.

The report's conclusions say that with the rapid aging of our population, unpaid caregivers will be even more essential. They need and deserve programs, training and resources to give them the skills and support to continue providing such loving personal care. Despite the challenges, Konopka, like many other caregivers, wouldn't have done it any other way. "Sure, it was hard, but I feel so blessed to have been able to care for him in the home and receive services from Hope Hospice. It's what he wanted, and that gives me great peace." +



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