



Nurses Supporting Family Caregivers

Caregivers need more guidance from nurses to perform increasingly complex tasks.

Throughout our nursing careers, we've focused on family caregivers, investing substantial clinical, educational, research, and policy expertise to better understand their contributions, experiences, and needs. From this effort, we've discovered two truths. First, according to *Caregiving in the U.S. 2015*, a report by the National Alliance for Caregiving and AARP, there are 40 million family caregivers who need support to do their crucial, complex jobs. Second, these caregivers need more guidance to perform the same tasks that made us tremble the first time we performed them as new nurses.

Sometimes caregiving begins suddenly after a hospitalization for an injury or a serious illness. Other times, it's a slow evolution, with the caregiver taking on more responsibility for a person who is becoming more physically or mentally frail. The length of care can vary from weeks to years, with the needs of the care recipient changing along with her or his rate of decline.

The just-released report from the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America*, calls for health care providers to see family caregivers "not just as a resource in the treatment or support of an older person, but also as both a partner in that enterprise and as someone who may need information, training, care, and support." Nurses are vital to this effort by recognizing family caregivers; assessing their ability, interest, and capacity to assist; engaging them and sharing relevant information with them; and addressing their health and support needs, making appropriate referrals if needed.

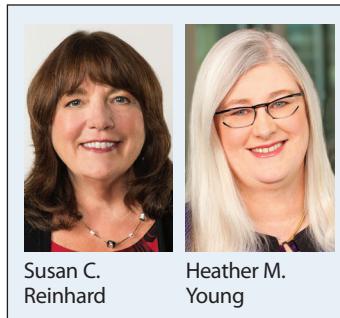
A few years ago, *Home Alone: Family Caregivers Providing Complex Chronic Care*, the first nationally representative study of family caregivers providing complex care activities published by AARP and the United Hospital Fund, showed us that half of caregivers were administering multiple medications (including injections), providing wound care, managing colostomies, inserting catheters, giving tube feedings, and more. The job description for a family caregiver has expanded from assisting with activities of daily

living and social support to include "medical/nursing tasks." This research changed the national conversation and prompted state action.

AARP state offices and other stakeholders are advancing new legislation that addresses the need to support family caregivers. This legislation, the Caregiver Advise, Record, Enable (CARE) Act—now the law in 33 states—focuses on hospital admission and discharge as an important first step in addressing caregivers' needs. Under the law, patients have the right to designate a family caregiver who is named in the patient's hospital record and involved in discharge planning. The hospital notifies the caregiver when the patient is to be moved or discharged and offers instruction on the medical and nursing tasks in the discharge plan.

Policy is helping to shape practice changes, but we need resources to support those changes. We created a new initiative: a Home Alone Alliance of organizations committed to producing such resources, including teaching videos. Our goal is to develop short, user-friendly videos that can be used by nurses as a teaching tool with family caregivers, and later accessed by the caregivers online and via mobile devices as they perform their tasks.

To this end, and in recognition of November as National Family Caregivers Month, we are pleased to partner with AJN to launch *Supporting Family Caregivers: No Longer Home Alone*, a series of articles and videos to help nurses answer caregivers' call for help. Each article will address a different aspect of medication administration and provide the evidence behind the practice depicted in the video. We encourage readers to use these tools in supporting family caregivers. Together, we can form a strong network of professionals and families who advance health care for those who need an extra hand. ▼



Susan C.
Reinhard

Heather M.
Young

Susan C. Reinhard is senior vice president and director of the AARP Public Policy Institute and chief strategist at the Center to Champion Nursing in America in Washington, DC. Heather M. Young is associate vice chancellor for nursing, dean, and professor in the Betty Irene Moore School of Nursing at the University of California, Davis, in Sacramento. Contact author: Susan C. Reinhard, sreinhard@aarp.org.