

**Spotlight**

# The CARE Act Implementation: Progress and Promise

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The Caregiver Advise, Record, Enable (CARE) Act became law in 40 states and territories in just four years, and additional states have initiated the legislative process. The swift uptake indicates policy maker recognition of the support family caregivers need to perform the medical/nursing tasks they face at home after a family member or friend is discharged from the hospital.

The landmark 2012 AARP and United Hospital Fund report *Home Alone: Family Caregivers Providing Complex Chronic Care*, funded by The John A. Hartford Foundation, drove the rapid policy adoption of the CARE Act. The report also inspired the creation of the Home Alone Alliance<sup>SM</sup>, a partnership of public, private, and nonprofit organizations coming together to change the way health care organizations and professionals interface with family caregivers.

This *Spotlight* provides an update on CARE Act implementation, bringing in views from the field. Future publications will highlight innovations and promising practices. Involving family caregivers during the hospital stay reflects a commitment to person- and family-centered care and improved outcomes for all people, regardless of their age or diagnosis, and for the family members, neighbors, and friends who support them.

## The Goal of the CARE Act: Drive Family Caregiver Guidance for Complex Care

In the rapidly evolving United States health system, where hospitalized people are discharged very soon after admission, family caregivers are expected to perform increasingly complex medical/nursing tasks, yet they feel ill prepared to take on this important role. This was a major insight from the landmark 2012 AARP and United Hospital Fund report *Home Alone: Family Caregivers Providing Complex Chronic Care*, funded by The John A. Hartford Foundation. For the first time, this national survey recognized a vital gap in

the supports and guidance available for family caregivers. Appropriately, this finding sparked great interest among many stakeholders, including family caregivers, health care professionals, researchers, the media, and advocates. Importantly, it struck a chord with policy makers as well.

Because approximately a quarter of households in the United States provide care to an older adult,<sup>1</sup> this topic resonated with individuals across party lines, across social and economic divides, and throughout our vast geography. Major caregiver organizations and experts at the state and national levels mobilized in support of the efforts of the AARP State Advocacy

and Strategy Integration team, providing input on the development of model state legislation. The result of this rapid translation of the *Home Alone* research into policy was the Caregiver Advise, Record, Enable (CARE) Act. In 2014, Oklahoma led the way by becoming the first state to make the CARE Act law; since then, 39 additional states and territories have enacted this model legislation (see Figure 1). In addition, several states have enhanced implementation of the CARE Act by developing new related regulations and embedding compliance in hospital quality assessments.

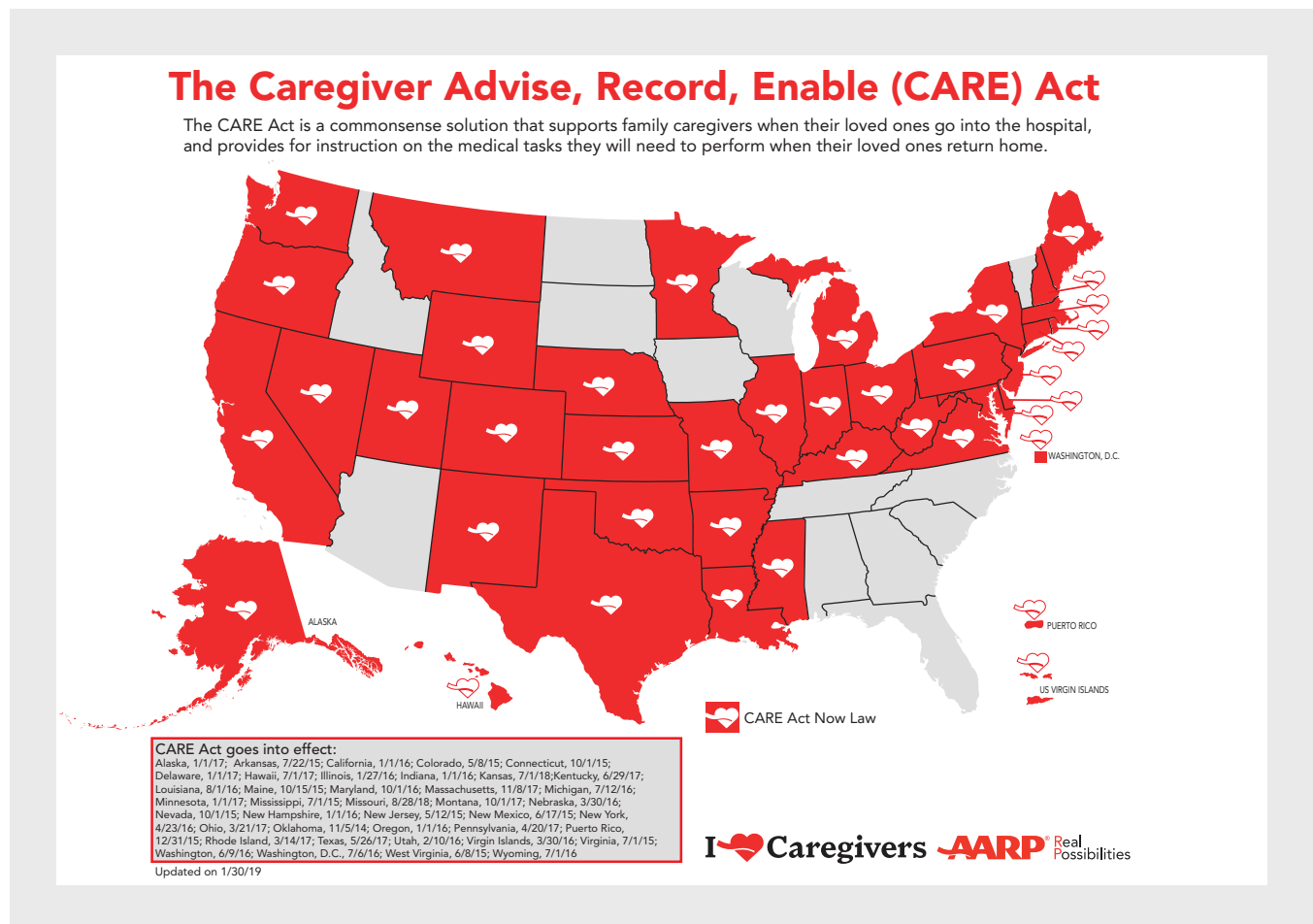
The CARE Act addresses fundamental expectations to support better communication between health care professionals and family caregivers as they prepare for complex care at home.<sup>2</sup> The name of the law and its specific provisions vary by state, but the

legislation generally requires that hospitals do the following:

- **ADVISE** individuals of their opportunity to identify a family caregiver.
- **RECORD** the caregiver’s name and contact information in the health record (with the patient’s permission).
- **ENABLE** family caregivers by providing as much notice as possible about discharge timing, consulting with them about the discharge plan, discussing their role in carrying out that plan, and instructing them about the medical/nursing tasks they will handle at home.

The speed of CARE Act adoption was remarkable—the result of compelling research, superb collaboration among stakeholders, and a strong

FIGURE 1  
CARE Act Map



strategy for widespread diffusion.<sup>3</sup> Starting with a clear and simple message, the collaborative process in each state moved the logistics forward. The AARP state offices played a vital role in shaping the proposed legislation at the state level, taking into account local forces and barriers; engaging consumers; and promoting a shared vision.

The timing of the CARE Act's emergence was ideal given trends in health care delivery as a result of the Affordable Care Act (ACA) of 2010. Because of the public policy drive toward value-based care and concerted efforts to reduce costs, the demands on post-hospital settings, including the home, had increased.<sup>4,5</sup> Motivated by ACA provisions to both reward high quality and lower cost, as well penalties that took effect in 2012 for hospitals with higher-than-expected rates of 30-day readmissions, hospitals began to identify and support those individuals most likely to be readmitted. As a result of this confluence of dynamics, a variety of approaches emerged, including transitional care programs and post-discharge support.

Thus, the stage was set for family caregivers to receive greater attention—both individually and collectively—as a vital component of the health care delivery system. The *Home Alone* study brought into clear focus the extent to which family caregivers were providing complex care and the significant gap between expectations and preparation. The CARE Act provides specific guidance for ensuring that family caregivers are seen and included in the care team by hospital staff.

With implementation of the CARE Act well underway and evidence of positive impacts emerging, this *Spotlight* provides an early look at where CARE Act implementation stands today—what it looks like on the ground in hospitals, how health care providers have responded, emerging trends, and other issues. In future papers, we will offer three approaches to explore progress in supporting family caregivers providing complex care:

- Identify major themes across hospitals, such as electronic health records and staff training, as summarized below.
- Elevate promising practices that address these themes.

- Spotlight health care systems that are implementing several promising practices simultaneously.

### Why Start with the Hospital?

Hospitalization can be a time of crisis and transition, especially for older adults and their family caregivers. New medication regimens and nursing procedures often result from an acute injury or exacerbation of a chronic illness. In a short period of time, older adults and their family caregivers need to absorb new information and learn how to perform novel tasks. Today, approximately half of family caregivers are performing medical/nursing tasks,<sup>6</sup> many of which are initiated during hospitalization. The hospital stay, therefore, is a critical time for collaboration and communication between family caregivers and hospital staff, who are ideally positioned to facilitate the learning and provide invaluable guidance.

That is not to say hospitals don't face challenges in this process. Major challenges to effective collaboration in the hospital setting include, first, identifying family caregivers and, second, successfully engaging them. What on the surface seems to be a simple issue—identifying the caregiver—is actually quite complex and potentially challenging. For instance, the term *caregiver* is not universally understood by health care professionals, consumers, and their families. Our working definition of *family caregivers* is “those who provide unpaid care to a relative or friend 18 years or older to help them take care of themselves.”<sup>7</sup> Stakeholders, from health care professionals to family members, may not understand that a caregiver can include someone who performs any of a range of functions: attending to personal needs and household chores, performing medical/nursing tasks, attending to financial issues, coordinating care, and supporting other aspects of daily function.

Hospitals have historically focused on identifying the next of kin (or emergency contact) and the durable power of attorney for health care decision making, neither of whom may be the person who will help manage care at home after discharge. Accurately identifying the family caregiver—and documenting this information so that staff know whom to include in sharing relevant information

during the hospitalization—is a vital logistical step for each hospital.

After a family caregiver is properly identified and all parties are made aware of the individual, the next challenge emerges: ensuring inclusion of the family caregiver in pertinent discussions about care and providing adequate guidance to him or her prior to the patient’s discharge. The CARE Act directly addresses these challenges by requiring hospitals to develop approaches to work with patients, to not only help identify the family caregivers but also include them in the pre-discharge planning process.

### Appropriate Family Caregiver Guidance in Acute Care

Ideally, hospital staff include family caregivers in discussions about care and assess their capacity to provide support after discharge. Assisting with medical/nursing tasks is usually in addition to helping with personal care known as Activities of Daily Living (ADLs) and household chores known as Instrumental Activities of Daily Living (IADLs). Family caregivers need information, guidance, and support on how to deal with these daily living tasks too, especially when the person needing care has dementia.

Assessment of family caregivers includes their capacity (e.g., time, physical capability), level of preparedness, and willingness and availability to provide assistance. Even when caregiving has already been a long-standing commitment, family caregivers might need guidance and support. Areas of priority for family caregivers include guidance on medical/nursing tasks, such as medications, wound care, assisting with mobility, special diets, pain management, using durable medical equipment, and other procedures. In addition, family caregivers require information on spotting indications of a problem, such as side effects of a medication or potential complications, as well as when and whom to call for help and how long to wait to call.

At discharge, family caregivers—often overwhelmed and stressed, and sometimes reluctant—need more than broad written instructions. The entire duration of hospitalization presents repeated opportunities for demonstration, discussion, and opportunity for the caregiver to perform the task and receive feedback (also known as *teach back*). These are all effective

ways prepare family caregivers. Between admission and discharge, family caregivers can benefit from the opportunity to observe nurses and other health care professionals as they complete the tasks the family caregiver will undertake at home and ask questions to gain a better understanding, take notes for reference, process the information, and discuss concerns that are specific to their particular situation. With notice of discharge as soon as possible, family caregivers have enough time to make arrangements to physically transport the person home, obtain and fill prescriptions, and purchase and set up equipment. Finally, given that family caregivers often must take in a great deal of information in a short period of time, they need to know whom to contact for further instruction and to answer questions once they are back home.

### The Home Alone Alliance<sup>SM</sup>

The *Home Alone* study also inspired a movement among a group of public, private, and nonprofit organizations that came together as the Home Alone Alliance<sup>SM</sup> (HAA) to work in concert with the implementation of the CARE Act and other strategies to support family caregivers who provide complex care. The founding partners of this alliance were the AARP Public Policy Institute, the Betty Irene Moore School of Nursing at UC Davis, the Family Caregiver Alliance, and the United Hospital Fund. Together, the founders developed a vision (Figure 2)

FIGURE 2  
Home Alone Alliance<sup>SM</sup> Focus Areas



to change the way health care organizations and professionals interface with family caregivers and recruited additional members (see Figure 3) that bring expertise, constituents, and support to the efforts.

The Home Alone Alliance<sup>SM</sup> is supported in part by AARP, The John A. Hartford Foundation, the Ralph C. Wilson, Jr. Foundation, the Retirement Research Foundation, and the CENTENE Charitable Foundation. Early activities focused on identifying resources to instruct family caregivers in medical/nursing tasks. Members of the Home Alone Alliance<sup>SM</sup> participated in a widespread environmental scan of existing instructional videos. They found that existing videos generally focused on a professional teaching a student or patient, typically in a clinical setting, and that none met a key criterion: the inclusion of a family caregiver learning how to perform a specific task. Identifying the paucity of resources, the AARP Public Policy Institute focused on collaborating with key Home Alone Alliance<sup>SM</sup> members to develop a series of videos, specifically for family caregivers that provide guidance in performing medical/nursing tasks. To date, we have published three series, covering wound care, mobility, and managing medications, with a total of 16 different topics; seven videos have Spanish versions (see Figure 4). These

videos can be found on the Home Alone Alliance<sup>SM</sup> website at [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone).

As a companion to these videos, the clinical experts have written scholarly articles published both as a special supplement for and in subsequent editions of the *American Journal of Nursing*. The *Supporting Family Caregivers: No Longer Home Alone series* comprises articles and the “how-to” videos that convey background evidence for the instruction in the videos as well as guidance for nurses (including tear-out tip sheets) to use in providing family caregivers with the tools needed to perform the care at home.

We also developed resource guides, which can also be found on the alliance website, for family caregivers to augment the video resources (see Figure 5). In addition to the *No Longer Home Alone* series, two new series on managing incontinence and preparing special diets will be available in mid-2019, and upcoming series will include using durable medical equipment, enhanced topics in medication management, and understanding a hospital stay.

The Home Alone Alliance<sup>SM</sup> is also cultivating collaborative relationships to advance system change and to disseminate resources for caregivers across health systems. For example, the GetWellNetwork,

**FIGURE 3**  
**Home Alone Alliance<sup>SM</sup> Members**

AARP*	<i>American Journal of Nursing</i>	Center to Advance Palliative Care	Atlas of Caregiving	National League for Nursing
Betty Irene Moore School of Nursing, University of California Davis*	African American Alzheimer’s and Wellness Association	Coalition to Transform Advanced Care	EMD Serono Inc.	National Alliance for Caregiving
United Hospital Fund*	New York University Rory Meyers College of Nursing	ElevatingHOME/ Visiting Nurses Association of America	Rosalyn Carter Institute for Caregiving	The Lindsay Institute on Caregiving/ Virginia Navigator
Family Caregiver Alliance*	Nurses Improving Care for Healthsystem Elders (NICHE)	Hartford Institute for Geriatric Nursing	Home Instead Senior Care Inc.	US Department of Veterans Affairs
The John A. Hartford Foundation**	Ralph C. Wilson, Jr. Foundation**	CENTENE Charitable Foundation**	Retirement Research Foundation**	Pfizer Inc.**

\* Indicates HAA founding partner


\*\* Indicates HAA funder

**FIGURE 4**  
**How-To Videos to Date**

Medication Management	Mobility	Wound Care
<ul style="list-style-type: none"> <li>• Beyond Pills: Eye Drops, Patches &amp; Suppositories</li> <li>• Dealing with Dementia-Related Resistance</li> <li>• Giving Insulin Injections</li> <li>• Hospital Discharge Planning*</li> <li>• Organizing and Administering Pills</li> </ul>	<ul style="list-style-type: none"> <li>• Preparing Your Home for Safe Mobility*</li> <li>• Getting from a Car to a Wheelchair*</li> <li>• What to Do When Someone Falls*</li> <li>• Using a Walker or Cane and Navigating Stairs*</li> <li>• Moving from a Walker to Shower or Bed*</li> </ul>	<ul style="list-style-type: none"> <li>• Treatment of Skin Tears</li> <li>• Pressure Ulcers: Prevention and Skin Care</li> <li>• Caring for and Maintaining Ostomy Bags</li> <li>• Diabetic Foot Care: Treatment and Prevention*</li> <li>• General Principles of Wound Care*</li> <li>• Caring for Lower Extremity Wounds and Cellulitis</li> </ul>

\* Denotes videos available in Spanish

**FIGURE 5**  
**Example of Resource Guide**



**PRESSURE ULCERS: PREVENTION AND SKIN CARE**

Pressure ulcers (also called bedsores, pressure sores, or decubitus ulcers) are skin wounds that are caused by poor blood circulation when a person must sit in a chair or stay in bed for a prolonged period. They usually develop over a bony part of the body. In this video the pressure ulcer is on the person's heel. Other common sites for pressure ulcers are the tailbone (the base of the spine), shoulder blades, hip bones, and the back of the head.

**Supplies for Treating a Pressure Ulcer**  
To treat a pressure ulcer, or to be prepared in case one happens, these are supplies to have on hand:

- Saline spray to clean the wound
- Dressing to cover the wound
  - Silicone dressing is easier to remove because it doesn't stick to the skin
  - Tape or gauze wrap to keep the dressing in place
- Disposable gloves
- Towel to support the person's body part and keep the surface clean
- Zip-lock plastic bags for disposal of treatment materials
  - Don't put used materials directly in the garbage
- Air-mattress or off-loading boot (if recommended by health care professional)

**Costs**  
Air-filled pillows or mattress and an off-loading boot that takes the pressure off the sore if it's on a heel may be useful. These are called "durable medical equipment" (DME). DME is covered by Medicare, Medicaid, and most insurance plans if a physician certifies that the equipment is "medically necessary." There may be deductibles and copays and you may have to use a specific vendor. If you purchase this type of equipment online, be sure to ask your health care provider exactly what is needed because there are many varieties to choose from.

**Steps in Treating a Pressure Ulcer**

1. Wash your hands thoroughly
2. Put on a fresh pair of disposable gloves
3. If there is an old dressing, remove it carefully
4. Place it in the resealable plastic bag for disposal
5. Cleanse the wound with mild soap and water or saline spray and pat dry
6. Remove your gloves and place in the disposal bag
7. Wash your hands again
8. Put on a fresh pair of disposable gloves
9. Put recommended product on the wound to keep it moist
10. Apply a clean dressing as prescribed
11. Use tape or gauze wrap to keep the dressing in place
12. Remove your gloves and place in the disposal bag
13. Make sure all materials are in the disposal bag
14. Wash hands again

**Signs of Infection**  
When changing the dressing, make sure you look for any signs of infection. These include:

- Redness
- Swelling
- Change in drainage
- Fever
- Chills
- Increased pain

If any of these occurs, and especially if you observe more than one, contact your health care professional immediately.

comprising over 200 hospitals, will feature the “how-to” videos among their online resources, available to both patients and families on a console at the bedside. The John A. Hartford Foundation, Ralph C. Wilson Foundation, CENTENE Charitable Foundation and The Retirement Research Foundation are all supporting further development and dissemination of resources to family caregivers.

Finally, the founding partners of the Home Alone Alliance<sup>SM</sup> collaborated on the next version of the *Home Alone* study, updating the survey to explore in more depth some of the important findings of the 2012 study. Funded again by The John A. Hartford Foundation, the survey was conducted in 2018, with an emphasis on oversampling multicultural caregiver voices. Results of *Home Alone Revisited* will be released at the 2019 American Society on Aging annual meeting in April.

**How Is Implementation of the CARE Act Going? A National Scan**

With the rapid adoption of the CARE Act, we wanted to know how hospitals have responded, what changes they have made in practice, and how these changes are affecting family caregivers. We assembled a

research team that included Home Alone Alliance<sup>SM</sup> and AARP Public Policy Institute leaders, nurse researchers, and policy experts to design and conduct site visits to answer our questions. Over the past two years, we have conducted 20 site visits with 18 health systems and 47 hospitals in Arkansas, California, Colorado, Illinois, Michigan, Nevada, New Jersey, New York, and Virginia. The team typically met with leaders and staff from at least 2 health systems per state and 2 to 3 hospitals per system. The team visited a variety of types of hospitals: nonprofit, for-profit, and government hospitals; academic health centers; midsize suburban systems; critical access hospitals in rural communities; and level I through V trauma centers. The number of hospital beds ranged from 25 to 837.

Participant informants included the chief nursing officer and others in a variety of roles, including chief technology officers and other senior leaders; service and unit managers; patient experience leaders; quality champions; administrators; educators; front-line nurses; social workers; physicians; electronic health record (EHR) leaders; and staff from areas such as discharge, social work, care transitions, Accountable Care Organizations,

pharmacy, registration, and admissions. We included representatives from patient and family advisory councils when possible, as well as individuals from a variety of community-based organizations, such as the hospital foundation and community agencies that serve older adults. During implementation, we consulted individuals from AARP state offices, other consumer advocacy organizations, professional groups, and state hospital associations. We conducted separate focus groups with family caregivers who had a recent experience with a particular hospital or system after implementation of the CARE Act and within the previous six months.

## Emerging Trends in Identifying Family Caregivers in the Hospital Setting

### Early Results

The initial site visits offered rich opportunities to learn about how the CARE Act is influencing practice. Many of the hospitals were very responsive to these visits, in part because hospital leaders and staff believed their organization already met the requirements outlined by the CARE Act. Nonetheless, these often exemplar hospitals reported that the process associated with the implementation of the CARE Act helped them recognize the benefits of standardizing, expanding, and formalizing their identification of and interactions with family caregivers. Their stated goals in implementing the CARE Act included decreasing hospital readmissions and increasing family caregiver confidence in and satisfaction with the care they were providing. Site visits will continue through at least 2020.

### General Takeaways Thus Far

During the site visits, hospital staff consistently reported that, subsequent to CARE Act implementation, family caregivers appeared more engaged and confident when taking the patient home. They added that, when they collaborated with family caregivers from the beginning of the hospital stay, family caregivers were more likely to ask important questions and provide the staff with information that would help ensure a person-centered holistic approach on the part of the hospital and successful outcomes after hospital discharge and even during the hospital stay itself. Leaders see the link between person- and family-

centered care and quality outcomes, and they value the CARE Act as a means to improve quality.

Important early efforts in hospitals' CARE Act implementation have often focused on the EHR and the work processes regarding admission and identification of a family caregiver. Clarity among the roles of family caregiver, durable power of attorney, and emergency contact facilitated better identification of the family caregiver. Importantly, successful ongoing engagement with the caregiver have required EHR design that ensured integration into usual care and discharge processes.

### Top 10 Themes

We will continue to conduct the CARE Act implementation scan to identify promising practices and ways to overcome barriers. Taking stock of our early findings across settings and states, we found that 10 major themes emerged in the conversations with stakeholders. These themes provide a glimpse into the complexity and value of CARE Act implementation. Each theme reflects an area of focus for hospitals as they planned for, implemented, and evaluated the CARE Act. These themes occurred simultaneously in the process. The themes with brief descriptions follow:

1. **EHR supports to identify and include the family caregiver:** The EHR is the foundational structure for standardizing and requiring identification of the family caregiver early in the admission process and then tracking and including the family caregiver throughout the hospital stay and discharge. Enhanced EHR supports include patient portals, messaging capacity, and modules for care coordination.
2. **Communication practices:** Communication is at the core of successful coordination of care and collaboration with family caregivers. Health systems approach the processes in numerous ways, including interdisciplinary rounds, team huddles, enhanced and inclusive shift change reporting, and white boards in the hospital room.
3. **Staff training:** Hospitals are recognizing the importance of staff training for important changes in care processes as well as a shift in perspective to include family caregivers in the care team. Most health care professionals were

socialized in models of care that focus primarily on the patient. Full inclusion of family caregivers requires education and process support.

4. **Learning resources for family caregivers:** With a greater focus on instruction and guidance for family caregivers, hospitals are using innovative approaches to facilitate learning. Several methods, including video-based instruction, a process of demonstration and teach backs, and enhanced tools and instructions, are effective.
5. **Approaches to making practice/system change:** Hospitals are experiencing dynamic change, driven by many forces—including the CARE Act, value-based payment, consolidation, and advances in technology. Organizations leverage these forces in innovative ways to change the way they practice and approach improvements.
6. **Pharmacy innovations:** Medications are a major element of any discharge plan, and family caregivers need specific guidance on how to help. New medications require reconciliation with the previous regimen, and instruction is needed for new medications. Pharmacists are responding—both individually and with innovative programs such as “meds to beds,” an effort to provide the first doses of medication prior to discharge.
7. **Transition in care programs and post-discharge support:** Because of value-based care and readmission penalties, post-discharge support has become a more routine aspect of care. Hospitals described a variety of ways they facilitate successful transitions, including enhanced social worker–nurse collaboration to plan the transition and anticipate needs, follow-up calls from nurses on the unit to the family caregiver at home, and connections to community resources.
8. **Screening practices:** An important element of effective care planning is identifying individuals at greater risk for complications or issues post-discharge as well as family caregivers who might need more assistance. Hospitals have implemented a variety of tools and strategies to identify those who should be prioritized for enhanced supports.
9. **Addressing the needs of specific populations:** The hospitals represent diverse communities and, within hospitals, the staff serve diverse patients with a range of health conditions, resources, and challenges. Hospitals described how they recognize and tailor care for specific populations, including using multicultural approaches, ensuring access for all languages, and addressing the needs of people with particular conditions such as dementia, chronic diseases, or heart failure.
10. **Benefits of the CARE Act:** Participants in the site visits identified many benefits of the CARE Act to their patients, family caregivers, and the organizations themselves. These include greater satisfaction and confidence with care transitions, reduced unnecessary rehospitalizations, and improved quality outcomes.

In summary, the changes resulting from the CARE Act are helping hospitals identify family caregivers and prepare them to successfully care for a family member at home after discharge—and help avoid problems that may result in preventable hospital readmissions. Hospitals are eager to learn about promising practices and willing to share their own.

### Future Steps

Several important activities are underway to fully implement the CARE Act and to advance supports for family caregivers, including the following”

- ▶ Continuing advocacy to advance the CARE Act in state legislatures in 2019 and beyond
- ▶ Releasing the results of *Home Alone Revisited: Family Caregivers Doing Complex Care* in April 2019 at the American Society on Aging meeting
- ▶ Continuing site visits in new states to learn about promising practices and to understand how practice is changing to support family caregivers across the spectrum, including conducting a deeper dive into communities in western New York and Southeast Michigan (funded by the Ralph C. Wilson, Jr. Foundation and The John A. Hartford Foundation)



- ▶ Completing and releasing new video series in collaboration with the *American Journal of Nursing*
- ▶ Releasing regular updates of this work, including a series of publications that elaborate on the 10 themes identified in the previous section, another series that spotlights effective practices with examples from the field, and spotlights on selected health care systems that are implementing several promising practices simultaneously to better support family caregivers providing complex care.

### Fulfilling the Promise of Person- and Family-Centered Care

Impressive momentum is driving change across the nation, making care more inclusive of family caregivers and ensuring that families get the information and support they need to continue in their caregiving role. The timing of the CARE Act and its implementation align well with other major current changes in health care delivery. These changes promise more responsive and personalized approaches for families dealing with complex health challenges.

The AARP Public Policy Institute and the Home Alone Alliance<sup>SM</sup> are pleased to share the sustainable advances in improving family caregiver interactions in the hospital setting and in building supports across organizations and communities for

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family caregivers who perform complex medical/nursing tasks.

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