

# BENEFITS OF THE CAREGIVER ADVISE, RECORD, ENABLE (CARE) ACT:

## 4 PERSPECTIVES ON ENHANCING PATIENT AND FAMILY ENGAGEMENT IN HOSPITALS

### ABOUT THE SERIES

#### *Supporting Family Caregivers Providing Complex Care*

The Caregiver Advise, Record, Enable (CARE) Act is now law in more than 40 states and territories. Policy makers recognize that family caregivers need support 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 rapid 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 US organizations coming together to change the way health care organizations and professionals interact with family caregivers.

Home Alone Alliance members are conducting a national CARE Act implementation scan to identify promising practices in hospitals and ways to overcome barriers. Some practices involve applying proven strategies to empower a new audience—family caregivers. Ten major themes emerged and provide a glimpse into the value and complexity of CARE Act implementation.

**The Supporting Family Caregivers Providing Complex Care series** includes 10 papers that highlight these themes. The series also features Promising Practice papers that provide specifics on a single practice in one health care system and Spotlight papers that describe innovative state efforts to promote change or a health care system that is implementing multiple practices simultaneously. See [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone).

These early snapshots from the field share insights about how hospitals are supporting family caregivers and open a dialogue among leaders involved in enhancing health care delivery. These early observations ultimately could inform practice recommendations.

### Overview

People are discharged from the hospital earlier in the recovery process than ever, leaving them in need of additional complex care at home. Family members and friends learn on their own how to deliver this care and perform the medical/nursing tasks previously provided by trained professionals.<sup>1</sup> When those family caregivers are not prepared, care recipients often experience pain and complications that lead to avoidable readmissions. Their family caregivers endure stress, guilt, and upheaval.

The commonsense CARE Act was designed to ensure family caregivers receive the guidance, instruction, and support they need to manage the postdischarge responsibilities they face at home.

**Hospitals leaders implementing the CARE Act report that engaging and educating family caregivers provides significant value for patients, families, clinicians, and health care systems.**

Hospitals consistently recognize that supporting family caregivers as outlined in the tenets of the legislation accomplishes the following:

- Aligns with person- and family-centered care goals;
- Leads hospitals to establish foundational processes that standardize family caregiver identification and support and give family caregivers the tools they need to be successful at home;
- Enables staff to learn about care recipient goals, values, fears, preferences, and responses to treatment and to manage family caregiver expectations about the difficulties of providing care at home;
- Reduces emergency department visits, readmissions, and the length of hospital stays;
- Ensures smoother and easier transitions between care settings by averting care gaps and omissions; and

- Decreases anxiety for people receiving care and their family caregivers by equipping and empowering them;

Some hospital supports and processes are new innovations. Others have become formalized or standardized as a result of the CARE Act.

## Identifying Themes from Hospital Visits

To learn how hospitals are supporting family caregivers after CARE Act implementation, we assembled a research team of Home Alone Alliance and AARP Public Policy Institute leaders, nurse researchers, and policy experts to design and conduct site visits to hospitals across the country. This work was funded in part by The John A. Hartford Foundation, the Ralph C. Wilson, Jr. Foundation, and AARP.

The research team has visited dozens of health systems and hospitals in Arkansas, California, Colorado, Illinois, Michigan, Nebraska, Nevada, New Jersey, New York, Virginia, and West Virginia. We typically meet with leaders and staff from at least two health systems per state and two to three hospitals per system. The team visits 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.

Participant informants include chief nursing officers, chief technology officers, service and unit managers, patient experience leaders, quality champions, administrators, educators, front-line nurses, physicians, electronic health record (EHR) leaders, and staff from areas such as clinical and social services, accountable care organizations, pharmacy, registration, and admissions. We consult individuals from family advisory councils, community-based organizations, AARP state offices, consumer advocacy organizations, professional groups, and state hospital associations. We conduct focus groups with family caregivers who have had a recent experience with a particular hospital or system. Interviews are recorded and then analyzed to identify common themes and novel approaches.

The intention of the [Supporting Family Caregivers Providing Complex Care](#) series is to describe the experiences of those making changes that align with the CARE Act. These early snapshots from the field describe the highlights of supports in place for family caregivers who provide complex care at home to a family member or friend after

### Emerging Themes of the *Supporting Family Caregivers Providing Complex Care* Publication Series

#### ➔ Benefits of the CARE Act

- Learning resources for family caregivers
- Staff training
- Communication practices
- EHR supports to identify and include family caregivers
- Transition in care programs and postdischarge support
- Approaches to making practice and system changes
- Pharmacy innovations
- Screening practices
- Addressing needs of specific populations

discharge from the hospital. The series opens a dialogue among health care leaders with a wide variety of perspectives. The papers share insights and could form the basis for future recommendations about supporting family caregivers.

## Hospital Leader and Front-Line Staff Reactions to the CARE Act

Throughout our ongoing national CARE Act implementation scan, we consistently see three primary reactions from hospital leaders and staff after integrating family caregiver support:

1. Health system leaders have long wanted to more actively support family caregivers, but they were not able to make that objective a priority until passage of the CARE Act.
2. Hospitals acknowledge that preparation for postdischarge care must take place throughout the hospital stay through formalized processes.
3. Nursing staff express that although initially they felt they already performed the work described in the CARE Act, they are surprised at how helpful it is to have a framework to enable consistency in family caregiver preparation—especially for people caring for older adults.

## 4 Stakeholder Perspectives: Highlights of CARE Act Benefits

Passage and implementation of the CARE Act continue to spark widespread culture change throughout US health care systems. During our ongoing national implementation

scan, hospital leaders and front-line staff report a multitude of benefits of the CARE Act. Preparing family caregivers to provide safe and effective postdischarge care offers significant value to family caregivers, care recipients, clinicians, and health care organizations.

 For Family Caregivers	 For Care Recipients	 For Clinicians	 For Health Care Organizations
1. Improved communication with clinicians	6. Increased ability to live independently	11. Increased comfort asking for family caregiver information	16. A person- and family-centered focus
2. Increased flexibility in their role	7. Smoother transitions from hospital to home or a long-term care setting	12. Streamlined staff communication with family members—focusing communication	17. Reduction in discharge delays
3. Decreased family caregiver emotional, practical, and financial strain	8. Deeper support when going home on hospice	13. Instructing the right person in postdischarge care	18. Improved quantitative success metrics
4. Enhanced continuity of care	9. Improved patient satisfaction	14. Improving quality by taking advantage of the knowledge family caregivers have about the person receiving care	19. Improved qualitative successes
5. Appropriate support at home to foster a successful recovery	10. Pharmacist support in the hospital, reconciling medication lists, and enhancing understanding of medications and how to manage them	15. More meaningful family engagement and increased job satisfaction	20. Early detection of complications to prevent problems that can lead to readmissions and penalties

### For Family Caregivers

#### 1. Improving communication with clinicians—

Communication and family caregiver preparation improves because family caregivers feel more empowered and engaged once they're formally identified and recognized in their role. EHR-based communication enhancements improve the consistency of communication between family caregivers and the multiple clinicians they receive information from.

**2. Gaining more flexibility in their role—**Because family caregivers are being asked about what they can commit to doing, they have the opportunity to work with hospital staff to discuss ways to fill any gaps.

**3. Decreasing family caregiver emotional, practical, and financial strain—**Family caregivers have less anxiety when hospital staff educate them about medical/nursing tasks, hospital processes, and

educational resources. They experience reduced strain and disruption of daily life during and after a family member's hospital stay; they are better equipped to manage complex care and pain, which is a major issue that carries an emotional as well as practical and sometimes financial strain.<sup>2</sup>

**4. Facilitating continuity of care—**A family may have multiple family caregivers who share responsibilities. A designated primary family caregiver can serve as the main point of staff contact to help ensure continuity of care before, during, and after a hospital stay. Continuity of care during all transitions within and outside the hospital helps ensure effective medication reconciliation and accurate and complete communication of patient-specific details, including values and preferences, and prevents care and communication gaps, errors, and omissions.

- 5. Arranging appropriate support at home to foster a successful recovery**—Early and ongoing conversations about postdischarge care enable staff and family caregivers to collaborate to determine what will be needed at home, such as the supplies and equipment necessary to manage medical/nursing tasks. Staff can provide referrals to community resources.

## For Care Recipients

- 6. Supporting independent living**—Because a person’s ability to continue living independently can depend on the care he or she receives following hospital discharge, it is particularly important for staff to collaborate with family caregivers who will help people with special needs or older adults remain at home long term.
- 7. Smoothing the transition from hospital to home or long-term care setting**—It is helpful for hospital staff to know if the person receiving care will have a temporary stay at another facility, such as a rehabilitation center, so they can provide information that will facilitate transitions to and from that setting. Better preparation for transitions helps care recipients avoid additional hospitalizations.
- 8. Getting the support they need when they go home on hospice**—Families often have little experience managing the end of life. When a care recipient goes home with hospice, staff members of the palliative care and hospice teams work with families to support and prepare them for the emotionally and physically demanding road ahead.
- 9. Improving patient satisfaction**—Survey comments from one hospital led the organization to conclude that “the CARE Act makes patients feel safer.” The process of actively including and assessing family caregivers helps build rapport and create trust, which leads to better interactions between staff and families, better outcomes, and increased satisfaction for all involved.
- 10. Getting pharmacist support in the hospital**—Conducting medication reconciliations during the hospital stay, ideally at each transition, promotes family caregiver understanding of how to understand, manage, and administer the medication regimen. This understanding helps prevent frequent and common medication errors, which can lead to avoidable readmissions.

## For Clinicians

- 11. Becoming comfortable asking for family caregiver information**—The CARE Act provides justification for asking older adults, in particular, to designate a family caregiver, driving most care recipients to share the information and have it recorded in the EHR. Staff can be more effective when they know who the primary caregiver is and when there are common expectations among staff and families.
- 12. Streamlining staff communication with family members**—Identifying a primary family caregiver gives hospital staff a single point of contact and prevents time and energy spent on repeating the same information to multiple family members. When large families want to divide caregiving tasks among multiple individuals, allowing extra time to designate a primary family caregiver is helpful. The EHR should distinguish between the primary family caregiver and additional family caregivers, with the option to change who serves as the primary caregiver over time.
- 13. Instructing the right person in postdischarge care**—Identifying the primary family caregiver allows hospital staff to focus their efforts appropriately. Staff report that rather than changing the substance of what they teach family caregivers, they are doing a better job of making sure the right person gets the right training for each task. It is important to document in the EHR specifics about what is taught to whom to enable hospitals to track what family caregivers learn and identify any gaps in their knowledge.
- 14. Improving quality by taking advantage of the knowledge family caregivers have about the person receiving care**—During live learning opportunities, family caregivers can share relevant details about the hospitalized person’s goals, values, fears, preferences, and responses to treatment. That information helps inform care plans and improve the quality and safety of care. Family caregivers can also bring to the staff’s attention subtle changes in the care recipient that signal a need for intervention. Having information about unique circumstances such as social determinants of health, known medication side effects, delirium, dementia, and substance use can be vital in developing a successful care plan.

**15. Increasing job satisfaction**—Collaborating with family caregivers gives hospital staff more context about the care recipient’s needs and enables them to more effectively prepare the family caregiver, leading to a better experience for all involved. Staff feel a great deal of pride in preparing family members to be successful at home.

## For Health Care Organizations

**16. Focusing on individuals**—Instructing family members who will perform medical/nursing tasks after a hospital discharge is sound policy, and it’s good for business.

Hospital leaders share that the CARE Act comes at a good time and aligns with recent overall focuses in health care delivery—including the Hospital Readmissions Reduction Program (HRRP), a Medicare value-based purchasing program; the national Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey of patients’ perspectives of hospital care; and Centers for Medicare & Medicaid Services (CMS) requirements related to meaningful use of certified electronic health record technology (CEHRT).

The CARE Act enables hospital leaders to provide a clear and consistent framework for multidisciplinary hospital staff to use as they help individual care recipients achieve their care goals by supporting family caregivers. This foundation takes into account the need to assess family caregiver willingness, availability, capabilities, and preparation for postdischarge care at home. Implementation of the legislation sets the stage for hospitals to train staff on how to identify, engage, and prepare family caregivers. It promotes collaboration among the entire care team, which includes the care recipient and family caregiver.

When people—especially older adults—experience multiple hospital stays, consistency in their experiences leads to loyalty, which prevents them from going to other hospitals that may not have access to their medical history in an EHR. Remaining with a single hospital system rather than seeking a better experience at another health care system leads to more consistent care, which leads to better outcomes and fewer postdischarge problems and avoidable readmissions.

**17. Preventing discharge delays**—Staff can provide and reinforce information gradually throughout the hospital stay—starting at admission—rather than delivering large quantities of information to distracted family caregivers during the flurry of discharge activity.

**18. Improving quantitative success metrics**—Hospital leaders attribute improvements such as these at least in part to the CARE Act:

- At one hospital, a nursing postdischarge follow-up call program increased the nursing domain portion of the HCAHPS patient experience score from 75.6 percent to 80.9 percent.
- At another hospital, results from the HCAHPS question about whether people get the information they need at discharge rose from 80 percent to 90 percent.
- A medication reconciliation program at one health system decreased medication discrepancies by 80 percent.
- One health system’s documentation of notifying the family caregiver about discharge or transfer increased from 42 percent to 72 percent, and its overall compliance with the CARE Act grew from 8 percent to 92 percent.

**19. Improving qualitative results**—Health system leaders and nurses across the country consistently report anecdotally that identifying, engaging, and instructing family caregivers results in a reduction in readmissions and improved patient experiences. Comments on one hospital’s patient satisfaction survey leads the hospital leaders to conclude that changes resulting from the CARE Act make patients feel safer.

**20. Detecting complications early to prevent problems that can lead to readmissions**—Hospital staff indicate that discharged individuals may be less likely to have a complication at home that requires an emergency department visit or hospital readmission when family caregivers are fully prepared.

## Implications of COVID-19

The COVID-19 (severe acute respiratory syndrome coronavirus 2) pandemic has revealed the profound importance of family presence on the health, well-being, and recovery of individuals during a hospitalization.

The absence of family caregivers during the pandemic underscores how much they normally contribute to day-to-day care in the hospital. Care recipients are left with little of the crucial emotional support family caregivers provide, resulting in loneliness and other negative effects on their mental and physical health.

Front-line staff are left to manage the day-to-day bedside tasks family caregivers often handle, such as helping those with a high fall risk to the bathroom, assisting with ambulation to prevent the loss of muscle mass, and encouraging patients to eat and maintain hydration. Staff also do not have the benefit of family caregivers alerting them about increasing pain or changes in mental status, which is especially important when the care recipient has dementia or delirium.

**To address issues related to COVID-19, some health systems do the following:**

- 1. Change visitation policies** to modify restrictions for essential family members and end-of-life visits;
- 2. Modify in-person encounters** to offer phone calls during rounds, foster intentional in-person connections during visits, increase home-visit safety, provide virtual support groups, and coordinate outreach during and after the hospital stay;
- 3. Adapt staffing models** to redeploy staff to the busiest areas, particularly to focus on connecting with family caregivers;
- 4. Use telephonic and video technologies** (with training and tech support) to enhance communication of instruction on postdischarge care; and
- 5. Deepen community partnerships** to mitigate strains families face, such as food insecurity and financial difficulty, that affect their ability to provide adequate, safe postdischarge care.

The timely launch of the [Supporting Family Caregivers Providing Complex Care](#) publication series highlights a wide variety of additional promising practices in family caregiver support just when they are most urgently needed.

## The Need

### Family Caregiver Support Is Essential for Today's Postdischarge Care

#### The CARE Act Addresses Challenges Family Caregivers Face

The gap between the complex postdischarge care family caregivers face and the preparation they receive to manage that care was established in [Home Alone: Family Caregivers Providing Complex Chronic Care](#), the research report published in 2012 by AARP and United Hospital Fund and funded by The John A. Hartford Foundation.<sup>3</sup>

To address that gap, AARP designed the Caregiver Advise, Record, Enable Act—now law in more than 40 states and territories. The legislation is designed to support the 20 million family caregivers who must learn, often on their own, to perform complex medical/nursing tasks at home for a family member or friend who is discharged from the hospital.<sup>4</sup> The name of the law and its specific provisions vary by state, but the CARE Act generally requires that hospitals take three specific steps to support family caregivers:

**1. Advise hospitalized individuals of their opportunity to identify a family caregiver.**

Patients and family caregivers often do not understand that hospitals expect them to undertake postdischarge medical/nursing tasks and other caregiving responsibilities at home.

**2. Record the family caregiver's name and contact information in the EHR (with patient permission).**

Clinicians across disciplines need easily accessible contact information to facilitate coordinated communication with family caregivers in preparation for discharge.

For additional details about the importance of family caregiver data in the EHR, see [Electronic Health Record \(EHR\) Practices to Improve Patient and Family Engagement: 9 Ways to Help Staff Access Data on Family Caregiver Discharge Preparation](#) in this publication series.

**3. 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 on the medical/nursing tasks they will handle at home.**

More than 8 in 10 family caregivers receive less than 24 hours' notice of discharge from the hospital.<sup>5</sup> More

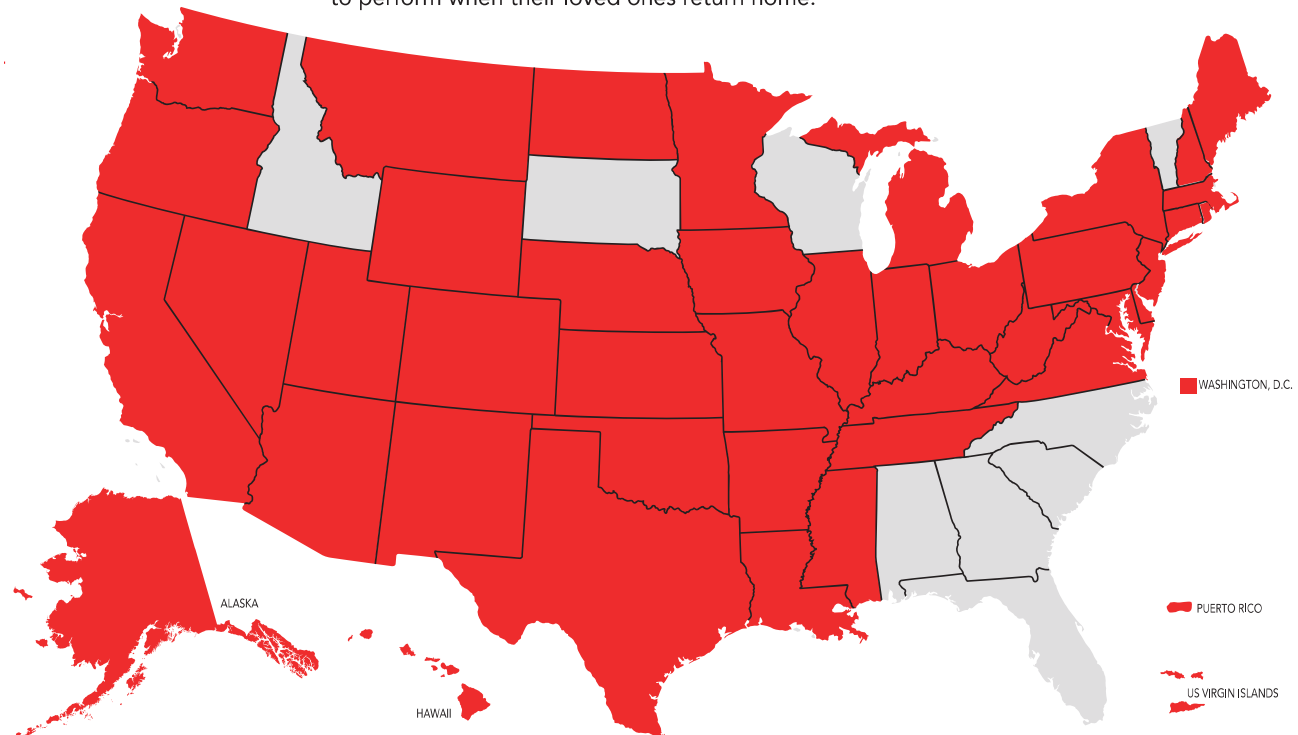
than half are given either no notice or less than 12 hours' notice.<sup>6</sup> This leaves family caregivers without enough time to prepare equipment, medications, and supplies at home and make arrangements to be available to provide what can be around-the-clock care.

This [CARE Act map](#) shows the more than 40 states and territories that have passed the legislation.



## The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved ones return home.



### CARE Act goes into effect:

Alaska, 1/1/17; Arkansas, 7/22/15; Arizona, 1/1/21; California, 1/1/16; Colorado, 5/8/15; Connecticut, 10/1/15; Delaware, 1/1/17; Hawaii, 7/1/17; Illinois, 1/27/16; Indiana, 1/1/16; Iowa, 7/1/19; Kansas, 7/1/18; Kentucky, 6/29/17; Louisiana, 8/1/16; Maine, 10/15/15; Maryland, 10/1/16; Massachusetts, 11/8/17; Michigan, 7/12/16; Minnesota, 1/1/17; Mississippi, 7/1/15; Missouri, 8/28/18; Montana, 10/1/17; Nebraska, 3/30/16; Nevada, 10/1/15; New Hampshire, 1/1/16; New Jersey, 5/12/15; New Mexico, 6/17/15; New York, 4/23/16; North Dakota, 8/1/19; Ohio, 3/21/17; Oklahoma, 11/5/14; Oregon, 1/1/16; Pennsylvania, 4/20/17; Puerto Rico, 12/31/15; Rhode Island, 3/14/17; Tennessee, 6/6/19; Texas, 5/26/17; Utah, 2/10/16; Virgin Islands, 3/30/16; Virginia, 7/1/15; Washington, 6/9/16; Washington, DC, 7/6/16; West Virginia, 6/8/15; Wyoming, 7/1/16

Updated on 10/21/2020

## Coping with Strain, Worry about Making Mistakes, Pain Management, and the End of Life

It's not just logistics that family caregivers must manage. The weight of the responsibility and worries of postdischarge care can leave family caregivers feeling overwhelmed to the point of being unable to cope with the tasks before them. Those among the most overwhelmed

are new family caregivers, those providing complex care, and those caring long term for someone with dementia.<sup>7</sup>

Consider these statistics from [Home Alone Revisited: Family Caregivers Providing Complex Care](#), a 2019 special research report created by the founders of the Home Alone Alliance<sup>SM</sup> and funded by AARP Foundation and The John A. Hartford Foundation:<sup>8</sup>

### **Half of family caregivers perform medical/nursing tasks.**

- About half of those family caregivers are afraid of making a mistake in their family member's care. Some racial/ethnic groups are markedly more worried than others. Multicultural family caregivers are more likely to experience strain and worry about making a mistake, regardless of income.
- Almost half feel down, depressed, or hopeless several times per week, compared with about a quarter of the general population of older adults. Twenty percent have no one to call for help; these caregivers are at higher risk for strain and depression.
- Seven out of 10 face the practical and emotional strain of managing pain, which carries an emotional as well as practical and sometimes financial strain. Witnessing the suffering of a family member is intensely stressful. In addition to the heartbreak of often being unable to ease pain, caregivers sometimes

need to cause further pain to help—by giving injections, removing bandages from wounds, or performing other invasive procedures. Identifying and easing the cause of pain can be a difficult process. The result is family caregivers coping with the additional strain of watching prolonged suffering.

Emotional strain is particularly deep for family caregivers managing pain that is severe. Pain medication requires constant monitoring and frequent adjustments, making pain management an ongoing unpleasant focus and adding to the stressful feeling of the loss of control for both the person being cared for and the family caregiver.

Many family caregivers must learn the intricacies of obtaining and administering opioid pain medications. The current concern about the overprescribing of opioids has led to difficulties in obtaining adequate pain relief, particularly for people whose chronic pain has been managed with opioids over time.

Family caregivers need guidance about what palliative care means and how it differs from hospice care. They need help understanding the shift from curative to comfort care. They need to have their expectations set about hospice before it is needed so they can take advantage of it as early as possible—with peace of mind. They especially need help learning the signs and symptoms of pain so that when the care recipient is unable to communicate at the end of life, the caregiver can feel confident they are providing adequate pain relief.

Many families do not have experience with the physical aspects of the dying process and do not realize how hard it is to manage the end of life. Even after families understand the philosophies and mechanics of palliative care and hospice, they are often not emotionally prepared to handle the day-to-day activities of hands-on care near the end of life. They worry about making a mistake that can precipitate death, especially when managing opioid medications. The anxiety and stress can lead to new or exacerbated health issues for the family caregiver.

### **What Family Caregivers Want**

The CARE Act aims to help hospital staff determine the context and goals of care—rehabilitation, management of serious illness or injury, or palliative or end-of-life care—and help mitigate the distress family caregivers endure by giving them the guidance, instruction, and support they need to provide effective postdischarge care at home.

When asked what would make it easier to perform medical/nursing tasks, the most common response from family caregivers across all tasks is more and/or better instruction—including additional exposure to the content, practice with supervision, written instructions, visual instruction, videos, consistent instructions, and a phone number to call with questions.<sup>9</sup>

One hospital's call center that identifies the issues care recipients inquire about after discharge found that questions about medication management are the primary reason for inbound calls.



## CARE Act Benefits and the Family Caregiver Experience: A Vignette

The example below illustrates an ideal family caregiver experience in the hospital.



**Example:** Shanice's physician schedules her for coronary artery bypass graft surgery and preadmission testing. The hospital

admissions department calls her to ask, "Who will help you at home after the hospital stay?" Shanice's son, Tyrone, agrees to help. Shanice and Tyrone go to the hospital a few days before the surgery. Shanice has preadmission testing and signs paperwork consenting to Tyrone's access to her health information. Tyrone participates in a family caregiver readiness screening regarding his willingness, availability, and preparation for postdischarge care. He receives an overview of his role as a family caregiver, which includes a discussion of the medications Shanice will be taking, wound care, and how the discharge process works.

The information from the screening is entered into the EHR on the system's family caregiver dashboard, which can be accessed by all interdisciplinary hospital staff caring for Shanice and preparing Tyrone to manage medical/nursing tasks for her at home. Flags in the system trigger outreach from a social worker to address barriers to successful family caregiving identified during the screening process.

Throughout the hospital stay, clinical and social support staff members record additional information and educational materials they give Tyrone at the bedside and by phone about wound care, medication management and administration, what good progress looks like, warning signs of complications, how to handle an emergency, and more. The information Tyrone receives

is appropriate for his language, race/ethnicity, culture, literacy level, and Internet access. He also receives information about how to manage the cost of medications, supplies, and equipment and how to get them in place before Shanice returns home.

The whiteboard in Shanice's room serves as a communication hub and has a phone number Tyrone can call with questions during and after the hospital stay. It lists daily updates about Shanice's anticipated discharge date and explains how to access her health information through the patient portal. When Tyrone cannot be at the hospital, Shanice or a nurse texts photos of the updated whiteboard to Tyrone.

Tyrone's time at the hospital is limited by his job and family responsibilities. A nurse makes appointments with him that work for his schedule for continued instruction using the teach-back educational method to confirm Tyrone's understanding, allow him to practice tasks over time with supervision, and provide opportunities to ask questions.

The discharge date is confirmed 48 hours in advance, allowing Tyrone to schedule time off work and finalize preparations for Shanice's care at home. During the discharge process, Tyrone receives a month's supply of all of Shanice's medications. Tyrone, a social worker, and a nurse meet to reinforce the information Tyrone received since the preadmission visit and confirm connections with community resources for ongoing support. The day after discharge, a nurse calls Tyrone to check on Shanice's recovery.

Shanice recovered safely at home. She and Tyrone both felt more prepared and confident and less anxious and overwhelmed than they had expected. They reported that their entire hospital experience could not have been better.

## Quantifying the Benefits

### Documenting What Success Looks Like

During site visits with health care organizations that are implementing changes to include family caregivers in the care process, we examined the impact of the enhancements. Although hospitals use scorecards and track many metrics, there was not universal identification of the direct link between family caregiver engagement and improvements in complication rates, emergency department visits, readmissions, follow-up inbound and outbound phone calls, and patient satisfaction.

An opportunity exists to set up a scorecard that monitors key metrics over time, with a special emphasis on linking family caregiver interventions to specific outcomes. Health systems can consider tracking and trending data by unit and department to measure the impact of including family caregivers throughout the hospital stay.

**Ultimately, the best measure of success is the experience of the family caregivers and whether they feel included, heard, confident, and prepared for the next phase of care at home.**

### Resolving Challenges of CARE Act Implementation

Below are examples of challenges to implementing the CARE Act and how hospitals overcome them.



**Challenge:** Front-line staff say, “We already do what the CARE Act requires.”



**Resolution:** Focusing on the requirements of the CARE Act helps hospitals recognize the need to standardize their identification and support of family caregivers. Initial concerns diminish when clinicians hear poignant personal stories about the existing gap between the information family caregivers who face extra challenges receive at hospital discharge and the care they need to provide at home. Listening to patient stories during patient and family advisory council meetings or in focus groups of community members reinforces the need for staff to consistently identify and provide detailed information to family caregivers. Content from the AARP *Home Alone* report creates additional awareness of process gaps.<sup>10</sup>

#### Staff Training Practices



**Challenge:** When leaders seek critical feedback about CARE Act implementation, the main concern they hear from staff is related to fitting additional training into busy schedules.



**Resolution:** Positive feedback after the training indicates that staff accommodate the training because they want and need the information so they can more deliberately include family caregivers in practices and workflows.



**Challenge:** Some hospitals experience high turnover, and new hires require training to understand the strategy, goals, and tactics of family caregiver guidance, support, and instruction.



**Resolution:** Modifying staff onboarding training to include training on Care Act requirements is a short-term effort that becomes self-sustaining in the long term.

#### Communication Practices



**Challenge:** Culturally appropriate materials in the language of the family caregiver are not always available.



**Resolutions:** Understand the needs of the populations each hospital serves and develop or obtain culturally appropriate materials. For example, one hospital uses tablets to videoconference with live translators when the appropriate in-person translator is not available. Others provide plain-language placards listing local and/or national family caregiver resources in family waiting areas and/or patient rooms, on-demand videos via the patient portal, online videos accessible before and after discharge, and DVDs. Make these resources available in the languages and consistent with the culture of those living in the local service area. Input from the patient and family councils can enhance the appropriateness of materials.



**Challenge:** Discharge information is voluminous and overwhelming.



**Resolutions:** Use simplified language, graphics, and formats to create the most concise and easy-to-understand material. Outbound calls after discharge offer family caregivers the opportunity to review the content, understand its importance, and determine how to address barriers to following the instructions.



**Challenge:** Poverty and low health literacy are barriers to family caregiver preparation, particularly for those caring for someone with a high-risk condition. One health care system serves a community that has a low rate of literacy, and about a third of residents in the community are not English speakers. Communication challenges in rural areas include geographic and transportation barriers and unreliable internet availability.



**Resolutions:** Use existing channels to involve social workers and interpreters. Modify EHR-based patient health literacy screening tools for use with family caregivers. Secure funding from nonprofit organizations for taxi vouchers and develop or find other resourceful means of helping family caregivers by partnering with community agencies.



**Challenge:** Caregivers are not always available during the day to receive instruction in the hospital.



**Resolutions:** Provide instruction during all shifts throughout the hospital stay as needed. Allow the patient to record bedside instruction to share with the family caregiver. Consider performing procedures at a time of day when the family caregiver can be present. Make specific appointments with the family caregiver to receive instruction.

### Transition in Care Programs and Postdischarge Support



**Challenge:** Discharge delays occur when family caregivers are not available for instruction at discharge.



**Resolutions:** Set a mutually convenient time to review discharge instructions or arrange for home health to provide family caregiver instruction after discharge. Promote the option of ordering skilled nursing visits that take place after discharge.



**Challenge:** Hospitals need additional case managers to provide navigational support to family caregivers and help them coordinate with learning medical/nursing tasks and arranging postdischarge support.



**Resolution:** Quantifying the costs of not providing this support and fiscal planning that takes these costs into account can promote the funding of services and supports that offset costs in other areas of the budget, such as unreimbursed readmissions.



**Challenge:** Some patients simply do not have an individual who can fill the role of family caregiver or are unable to name a family caregiver because they have dementia or are unconscious.



**Resolution:** At many hospitals, a nurse can select an EHR option such as “Patient declined” or “Unable to respond” on a documentation screen; the case management or social work department automatically receives a request for a consult to assist such patients and those who do not have a family caregiver.

### Approaches to Making Practice and System Changes



**Challenge:** Hospitals must decide how to begin making changes to long-standing processes.



**Resolutions:** Some hospitals start changing processes in one or two units; some begin with a systemwide approach. Successful changes include communications about culture change from senior leaders.



**Challenge:** Family caregiver education is not documented in one place in the EHR.



**Resolution:** Working with the EHR provider or internal IT team to reconfigure the display of family caregiver data, assessment of readiness, and instruction into a more easily accessible view enhances staff interactions with family caregivers and ensures professionals know where to find the information.



**Challenge:** Staff members involved in the discharge process (primarily nurses, discharge planners, and case managers) note concerns that new processes would be restrictive and create an additional burden for already maximized workloads.



**Resolution:** Hospitals manage the change process by examining the discharge planning workflow, streamlining processes, and clarifying and standardizing the language staff use to identify family caregivers.

### Pharmacy Innovations



**Challenge:** There are not enough resources to provide the ideal level of medication support to every family caregiver.



**Resolutions:** Hospitals provide medication reconciliations and instruction throughout the hospital stay at times convenient for pharmacists and family caregivers, giving care recipients and family caregivers a greater level of understanding about how to manage medications and confidence in doing so. Hospital staff anecdotally report significant decreases in medication discrepancies by having a standard process. Hospitals also scale approaches over time. Some hospitals tie interventions to a specific need. An example is prioritizing postdischarge calls to those with high-risk conditions who are identified as having low medication adherence and literacy.



**Challenge:** At discharge, family caregivers often cannot process information about medication regimens because they are caught off-guard about the level of responsibility they face or are too anxious to digest information.



**Resolutions:** Provide instruction and support throughout the hospital stay. Physicians prescribe home health support so patients and family caregivers get skilled nursing instruction at home shortly after discharge. This path is particularly helpful for patients with Medicare, who will likely receive the skilled nursing support at home at no charge. A home health professional can also help family caregivers create a medication management system that works for them and helps ensure adherence.

### Screening Practices



**Challenge:** There are not enough resources to provide the ideal level of support to every family caregiver.



**Resolution:** Hospitals increasingly innovate to provide instruction to support family caregivers. To put supports in place during the hospital stay and afterward, some health care systems develop close working relationships or partnerships with community-based organizations that focus on a specific population or condition.

### Addressing Needs of Specific Populations



**Challenge:** Family caregivers often cannot process information well in the hospital setting. Issues include language barriers and varying levels of literacy and health literacy.



**Resolution:** At some hospitals, prescribers increasingly write orders for home health support so patients and family caregivers receive skilled nursing instruction at home shortly after discharge. Instruction can be more effective in a calm, familiar setting after the peak of a medical crisis. This path can be particularly helpful for patients with Medicare and/or Medicaid, who may qualify to receive skilled nursing support at home at no charge.



**Challenge:** It is difficult to convince people who have a life-limiting condition to create advance care planning documents.



**Resolution:** The palliative care team at one hospital conducts family care conferences for the 80 percent of their patients who go home with hospice. They also allow time for staff to talk with families about creating documents such as provider orders for life-sustaining treatment (POLST) and do-not-resuscitate/do-not-intubate (DNR/DNI) orders and advance directives to help the individual, family members, and care team have a common understanding of end-of-life wishes.



**Challenge:** There is a significant lack of awareness in the community and sometimes in hospitals about how to manage care for people with dementia. The information gaps in the community can result in unnecessary hospitalizations.



**Resolution:** One health care system partners with multiple community organizations that focus on dementia. Social work staff developed and launched a seminar on aging that was open to the public. The traditional view of family is changing to include neighbors and friends—especially for older adults—so they also encourage attendance by friends and neighbors of those with dementia.

## Additional Information

### Helpful Resources

#### Researcher Contact Information for Health System Leaders

The Home Alone Alliance and AARP Public Policy Institute leaders, nurse researchers, and policy experts continue to conduct the national scan of hospitals that have implemented the CARE Act and will share further results of that work.

We welcome the opportunity to discuss findings with health system leaders to facilitate the culture change involved in fundamentally integrating family caregivers into existing hospital practices. To contact us, please email [homealonealliance@aarp.org](mailto:homealonealliance@aarp.org).

#### Free Video Demonstrations of Medical/Nursing Tasks for Family Caregivers

How-to videos and printable resource guides created specifically for family caregivers show how to manage specific tasks related to wound care, mobility, managing medications, preparing special diets, and managing incontinence. These resources, many of which are available in both English and Spanish, are free of charge to all. Visit [aarp.org/nolongeralone](http://aarp.org/nolongeralone).

#### Education and Tools for Professionals, Clinicians, and Policy Makers

To see details and data about the 20 million family caregivers in the United States who perform medical/nursing tasks and worry about making a mistake, see [Home Alone Revisited: Family Caregivers Providing Complex Care](#), a 2019 special research report by the [Home Alone Alliance](#).<sup>11</sup>

The [Supporting Family Caregivers Providing Complex Care](#) series of publications is based in part on insights in [Home Alone Revisited](#) and [The Care Act Implementation: Progress and Promise](#), a 2019 AARP Public Policy Institute Spotlight report.<sup>12,13</sup>

The [American Journal of Nursing \(AJN\)](#) publishes award-winning evidence-based, peer-reviewed articles and videos that teach clinicians how to best support family caregivers. *AJN* also disseminates the work of the Home Alone Alliance to nurses through editorials, podcasts, and social media content. Home Alone Alliance articles approved for continuing education credit are funded by AARP, The John A. Hartford Foundation, the Retirement Research Foundation on Aging, and the Ralph C. Wilson, Jr. Foundation.

The [National League for Nursing \(NLN\)](#) offers simulation modules that nurse educators can use at no cost to teach students about the individualized needs of family caregivers. The Advancing Care Excellence for Caregivers (ACE.C) program was developed with generous funding from The John A. Hartford Foundation and the AARP Foundation.

### Theme Papers in This Series

- [Transitions in Care and Hospital Discharge Practices to Improve Patient and Family Engagement: 16 Ways to Prepare and Support Family Caregivers](#) (PDF)
- [Approaches to Making Practice and System Changes to Improve Patient and Family Engagement: 12 Ways Hospitals Integrate Family Caregiver Support](#) (PDF)
- [Pharmacy Innovations to Improve Patient and Family Engagement: 10 Ways Hospitals Help Family Caregivers Prepare to Manage Medications](#) (PDF)
- [Screening Practices to Improve Patient and Family Engagement: 5 Ways Hospitals Prioritize Family Caregivers Who Need Extra Support](#) (PDF)

Additional publications in the Supporting Family Caregivers Providing Complex Care series are available at [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone). For more information about the CARE Act, visit the AARP Public Policy Institute website or <https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html>. To learn more about the Home Alone Alliance, visit [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone).

## Series Authors

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<sup>1,2</sup> Susan C. Reinhard et al., *Home Alone Revisited: Family Caregivers Providing Complex Care* (Washington, DC: Home Alone Alliance, 2019), <https://www.aarp.org/ppi/info-2018/home-alone-family-caregivers-providing-complex-chronic-care.html>.

<sup>3</sup> Susan C. Reinhard et al., *Home Alone: Family Caregivers Providing Complex Care* (Washington, DC: AARP Public Policy Institute, 2012), <https://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html>.

<sup>4-6</sup> Susan C. Reinhard et al., *Home Alone Revisited*.

<sup>7</sup> Janice F. Bell, Robin L. Whitney, and Heather M. Young, "Family Caregiving in Serious Illness in the United States: Recommendations to Support an Invisible Workforce," *Journal of the American Geriatrics Society* 67 (2019): S451-56.

<sup>8,9</sup> Susan C. Reinhard et al., *Home Alone Revisited*.

<sup>10</sup> Susan C. Reinhard et al., *Home Alone*.

<sup>11,12</sup> Susan C. Reinhard et al., *Home Alone Revisited*.

<sup>13</sup> Susan C. Reinhard et al., *The CARE Act Implementation: Progress and Promise* (Washington, DC: AARP Public Policy Institute, 2019), [aarp.org/ppi/info-2017/from-home-alone-to-the-care-act.html](http://aarp.org/ppi/info-2017/from-home-alone-to-the-care-act.html).

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