APPROACHES TO MAKING PRACTICE AND SYSTEM CHANGES TO IMPROVE PATIENT AND FAMILY ENGAGEMENT:
12 WAYS HOSPITALS INTEGRATE FAMILY CAREGIVER SUPPORT

Overview

Health care organizations differ greatly in how they approach hospital practice improvements. The drivers of change are complex, and the way organizations leverage those forces depends on their structure, population, and specific goals. Dynamics include COVID-19 (severe acute respiratory syndrome coronavirus 2), value-based payment, readmission penalties, consolidation, and advances in technology.

The CARE Act drives changes that support family caregivers—people in the patient’s social support system who provide care at home after discharge. These family members, friends, and neighbors are expected but often not equipped to perform medical/nursing tasks at home that were traditionally handled by trained professionals in the hospital.

Hospital leaders use various approaches to prepare family caregivers to provide safe, effective care at home and avert complications that can lead to readmissions. They use one or a combination of the following strategies:

- Integrate work into existing committees or convene a new interdisciplinary team.
- Focus work through the lens of one functional area, such as quality improvement, information technology (IT), clinical, or operations.
- Conduct a pilot program first or integrate change across an organization from the outset.
- Create a complete care continuum by connecting with home health and community organizations.
- Focus on one aspect of care, such as medications, which are challenging for family caregivers to reconcile, understand, manage, and administer.
- Modify the way they make practice and system changes given their experiences with COVID-19.

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 AllianceSM, 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.

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.
This paper shares promising practices and considerations for approaches to more effectively include family caregivers in the care process from preadmission through postdischarge care. Some supports were in place before the CARE Act and changes simply facilitated consistency across an organization.

**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, identifying 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 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.

**The Need**

**Family Caregivers Provide Medical/Nursing Care after Discharge**

Today’s family caregivers do more than provide postdischarge assistance with activities of daily living (ADLs), like walking and bathing, and instrumental activities of daily living (IADLs), such as shopping and cleaning. They also manage medical/nursing tasks like caring for wounds; managing feeding tubes and intense pain; and administering pills, suppositories, and injections.

Family caregivers often don’t have the knowledge, skills, competencies, time, or financial resources required to provide the complex care they face. They are often surprised to discover they are expected to provide care and are sometimes unable to provide it. The disconnect between the expectations of hospital staff and family caregivers leaves a gap that hospital leaders increasingly work to fill.
More than 20 million family caregivers perform complex medical/nursing tasks at home after discharge. To provide good care safely, family caregivers need to understand their role and how to fulfill it. Hospitals are challenged with providing that information systematically—meeting the needs of diverse populations and factoring in family caregiver willingness and ability as well as cultural, family, and mental and physical considerations and barriers.

Time is of the essence. Family caregivers often have little notice of hospital discharge. This leaves little time for family caregivers to prepare equipment, medications, and supplies at home and make arrangements to be available to provide what can be around-the-clock care. Family caregivers will often receive an overwhelming amount of instruction about follow-up care in a very short time. This information is delivered among the rush of discharge activities, making it difficult for family caregivers to remember a multitude of details.

Gaps in Family Caregiver Preparation Affect Multiple Stakeholders

At home, lack of family caregiver preparation can lead to complications that bring decline and intense pain for the person receiving care, family stress and guilt, and upheaval when a complication becomes a medical emergency. It can even trigger a cascade to dependency and nursing home placement.

For hospitals, lack of family caregiver preparation can lead to discharge delays, costly postdischarge emergency department visits, and unreimbursed readmissions—affecting hospital processes, workflows, and financial health.

Prior to CARE Act implementation, many health care systems did not have supporting policies and structures to identify and support family caregivers. Many front-line staff were not aware that a family caregiver readiness gap existed at discharge and there was usually no formal process for them to receive feedback from family caregivers after discharge. Integrating family caregiver support can require a paradigm shift for front-line staff from simply documenting emergency contact information and providing discharge paperwork to consistently identifying, preparing, and instructing the person who will provide care at home after discharge.

A similar shift is needed among people living in the community to understand the difference between a family caregiver and a legal surrogate—to prevent what is often a lengthy discussion to sort through the differences between those roles.

12 Highlighted Practices

Ways Hospitals Approach Integrating Family Caregiver Support

Our ongoing national CARE Act implementation scan identified successful approaches hospitals take to help family caregivers provide safe, effective care at home and avert complications that can lead to readmissions. Hospital leaders use one or a combination of these strategies. Some initiatives are a direct result of the CARE Act. Some supports were already in place and many are enhanced to achieve consistency across an organization.

Health care systems are modifying the way they make changes. Given the rapidity with which hospitals began pivoting at the beginning of the coronavirus pandemic, leaders have become more agile in making changes to adapt to national guidance and the updated evidence as they see what works best.

Determining How to Organize the Work

1. **Consult with hospital associations, front-line staff, patients, and family caregivers.**

   Hospital leaders gather the input of stakeholders from hospital associations to front-line clinicians and staff, patients, and family caregivers. Staff surveys not only elicit feedback from staff who work directly with patients and family caregivers, but also inspire individual ownership and pride in implementation when that input is applied. One hospital’s philosophy is that asking front-line staff for input produces the most effective ideas and implementation. It developed a grid and asked staff to fill in what they need, what the focus of their work with family caregivers should be, and how to support integrated care management.
Approaches to Making Practice and System Changes to Improve Patient and Family Engagement

Hospital leaders express interest in learning about EHR modifications that other organizations make. There is an opportunity for hospitals to collaborate with their EHR vendor to learn more about how other organizations support family caregivers.

2 Enhance communication and preparation while balancing competing priorities.

Hospital leaders recognize that guiding and instructing family caregivers requires enhanced communication and care coordination throughout the hospital stay—among patients; family members; and clinicians such as physicians, nurses, social workers, and physical therapists. They analyze and incorporate ways to facilitate that communication, particularly between nurses and social workers.

They evaluate how to enable nurses to devote time to family caregiver communication and instruction while supporting competing priorities that include the fundamental organizational focuses on efficient patient flow and providing excellent routine and acute health care for multiple patients.

Improved communication with family caregivers addresses the common complaint from family caregivers about communication gaps and inconsistencies during a hospital stay—relative to both procedural and emotional aspects of caregiving.

3 Integrate work into existing teams or convene a new interdisciplinary team.

Depending on the organization’s structure, population, and business goals, some health care systems segment the work involved in providing family caregiver support and integrate it into multiple existing committees while others create a new interdisciplinary team with a singular focus.

One large health care system uses both a large interdisciplinary steering committee and existing standing committees. The health system includes family caregiver ambassadors as team members to provide input about care issues and the effectiveness of the organization’s patient portal.

Communication Challenges and COVID-19

Changes resulting from the COVID-19 pandemic create new barriers to communication among staff, those receiving care, and family caregivers. However, as organizations rethink many aspects of care delivery, the opportunity exists to take a fresh look at all aspects of communications with family caregivers. With the uncertainty of the pandemic, the need for constant and consistent communication is more important than ever. Clinicians can examine questions such as how instruction will take place when family caregivers are not allowed at the bedside and who will determine what that content will include relative to COVID-19.

Additional complexity is involved with COVID-19-related limits or restrictions on “visitors.” That focus provides an opportunity for health care systems to educate staff, patients, and family caregivers about the differences among next of kin, legal guardian, and family caregiver to determine if those descriptors refer to one individual or to two or three different people. This will help everyone involved determine who should be the one person hospitals may allow to accompany someone receiving care in the hospital. This differentiation will also help prevent staff from providing information to someone who should not have access to it. Hospitals can also consider permanently adopting creative uses of technology that facilitate communication among those receiving care, clinicians, and family caregivers.

4 Choose one or more functional areas to drive the changes.

Some health care systems select one functional area to be the primary lens through which they implement family caregiver preparation for postdischarge care.

Areas that hospitals may choose as a starting point include infection control, quality improvement, safety, satisfaction, clinical, case management, information technology, finance, and operations. Some hospitals choose two or more interdependent areas, such as clinical and IT, to enable consistent family caregiver identification and documentation. They drive changes through the work of the chosen functional area.
One health care system leveraged its existing clinical performance work to launch a multigoal, systemwide effort. Goals include improving safety, outcomes, and patient experience by reducing hospital readmissions; improving appropriate utilization of hospice and palliative care; reducing the rate of hospital-acquired infections; eliminating adverse events in operating rooms; and improving patient access to care. Most of those goals directly involve family caregiver support.

Mergers necessitate change. Some consolidating hospital systems form a new interdisciplinary team—which includes IT because of its relevance to all functional areas—with members of both systems to identify best practices and map processes and workflows.

Integrate change into the workflow, change the workflow itself, or add services.

To achieve goals related to improving family caregiver support, some hospitals embed changes into existing workflows while others deconstruct then reconstruct workflows. Some hospitals even add additional clinical and physical resources.

Integrating change into the workflow
Some hospitals implement changes to the EHR that incorporate family caregiver preparation activities into existing workflows.

Changing the workflow itself
One hospital system changed a workflow by creating a new unit-based case management structure and performing initial family caregiver assessments within 24 hours of admission. It holds daily interdisciplinary staff meetings to discuss patient progress from clinical, psychological, and social perspectives, then updates the family caregiver. Staff document the discharge plan and other details on the white board in the patient’s room. The health system piloted the program in one unit and eventually rolled it out to all units.

Adding clinical resources
Other hospitals develop robust transition suites staffed by full-time, dedicated nurses. Before leaving the hospital, family caregivers can practice with supervision the medical/nursing tasks they will perform at home. They can also get help finding the medications they need at prices they can afford. After discharge, transition suite nurses make follow-up calls and review discharge information, confirm family caregiver understanding, and answer questions.

Another hospital added a resource center for family caregivers that provides education and interdisciplinary clinical support, including guidance about decision making.

Position responsibility for family caregiver support as nursing practice.

Hospitals focus on ensuring smooth workflows for front-line staff. Pivots that actually enhance workflows include moving the start of family caregiver support—correct identification—to earlier in the hospital stay. Virtually all hospitals agree initially or eventually that because nursing is the driving force of family caregiver preparation, family caregiver instruction, guidance, and support should be led through nursing practice.

Deliver culturally appropriate support.

Many health care systems serve geographic areas that have significant cultural and socioeconomic diversity. Meeting the needs of diverse populations means factoring in cultural, family, and mental and physical considerations and barriers as well as family caregiver willingness and ability. It also means recognizing factors such as these: one in four family caregivers is a millennial, and 40 percent of millennials and younger caregivers are supporting someone with a behavioral health condition.

Some programs segment patient–family caregiver dyads to support them appropriately according to age; language spoken; communication barriers resulting from cultural norms; whether they have needs relevant to being part of a group such as the lesbian, gay, bisexual, transgender, and questioning community; or other criteria.

Leaders at one hospital noted that Spanish-speaking family caregivers are often much more involved in the patient’s care because of cultural norms in their communities. With that knowledge, clinicians can communicate differently with family caregivers who at the outset are more engaged compared with English-speaking family caregivers, who have lower expectations about their hands-on involvement because of their cultural norms.
Hospitals provide discharge instructions that vary by health condition and the education level of patients and family caregivers. They also develop information that is culturally appropriate for and translated into numerous languages. Some hospitals work with external vendors to provide multicultural content.

**Determining How to Implement the Work**

8 **Start with systemwide integration.**

Some hospitals decide from the outset to implement changes across an organization. Large-scale projects typically move more slowly than pilot programs, but they change organizational culture across the board so all staff members at every step of the hospital stay approach their work using the same person- and family-centered mindset. That consistency improves the hospital experience for those receiving care and for family caregivers. It also improves the staff’s workplace experience. Consistency is especially important in large organizations because of the many inherent opportunities for communication to break down; family caregiver support is most effective when staff in all roles communicate with family caregivers with the same goals in mind.

One large health system recognized early in its CARE Act implementation that given the size and complexity of its organization, it needed a systemwide effort led by its nursing staff.

One health care system emphasizes establishing strong relationships between staff and families. That valuable nuance underpins and furthers the work that staff across roles do as they compare patient needs with family caregiver capabilities, fill in the gaps, and document progress for all involved to see. This type of organizational culture is quickly evident to and adopted by new staff members, which is especially helpful for organizations with high turnover.

9 **Start with a pilot program.**

Some leaders create small short-term projects that use nimble process improvement cycles that include a continuous feedback loop, quick pivots, and scalability. Hospitals replicate successful pilot programs by various criteria, such as by unit, building location, population segment, patient risk level, and status—inpatient, outpatient, or observation. Scaling can take the form of multiple short-term projects or one long-term initiative.

One health care system developed an internal partnership between research and operations to arrange a patient visit with the primary care provider within a week of discharge. The goal of this appointment is to follow up on details of the hospital stay rather than to focus on routine care. The program began in a cardiac unit because of postdischarge issues with medication management and now also supports other patients at high risk.

Another system has an accountable care organization (ACO) clinical laboratory that develops strategies for scaling successful pilot programs for ACO patients. In one approach, the hospital-based care team participates in follow-up care. Patients receive a phone number for the nurse coordinator, a follow-up...
Appointment with a primary care physician, and 30 days of medication. The goal is to then roll out successful ACO programs to all patients.

**10. Create a self-contained care continuum or partner with community organizations.**

Hospital leaders and staff explain that, ideally, discharge planning should start before hospital-based care takes place—by providing education and expectation-setting messaging throughout the community they serve. Large integrated systems coordinate their education initiatives across the various settings in their self-contained care continuum.

To simulate a self-contained care continuum, hospitals forge partnerships with external health care–related services and organizations that provide care in the community and at home. They develop interconnected workflows that help staff at all of the organizations ensure that family caregivers take advantage of resources available to them and the person they are caring for. At one hospital, social workers partner with an organization that cares for older adults to give educational seminars in the community to engage family caregivers.

Hospital staff share that the goal is for everyone, not just inpatients, to have a care coordinator and a care plan based on family and social history and extending beyond an isolated hospital-based event. Information should remain accessible to all involved and follow individuals across settings and over time.

Health care systems have an opportunity to partner with community-based case management and other organizations to create public awareness of the agencies and services. The partners can also work together to generate data and analytics that will help the community organizations obtain new grants.

**11. Focus on medications.**

Medications are challenging for family caregivers to afford, understand, reconcile, manage, and administer.

At some hospitals, pharmacists conduct a medication reconciliation at some point during the hospital experience—from admission to postdischarge follow-up calls for those identified as having low medication adherence and literacy. Pharmacists involve family caregivers in discussions when possible to seek input, answer questions, ensure there are no discrepancies, and encourage adherence.

In a hospital where admissions come primarily from the emergency department, pharmacy technicians review medications before the person receiving care is seen by a physician or nurse practitioner. Having a thorough, current medication reconciliation available for physicians and nurse practitioners as they conduct a history and physical examination gives them critically important details about a patient that they would not have otherwise. This additional knowledge is especially helpful during clinical evaluations of high-risk and frail older adults and those taking multiple medications.

In some hospitals, especially those with experience proactively supporting family caregivers, staff pharmacists meet in the hospital room with those receiving care to conduct a medication reconciliation. The pharmacists encourage family caregivers to participate in the discussion. During residency, pharmacists meet with patients regularly as a standard part of their training.

When an affordability issue occurs, discharge nurses call prescribers to arrange a substitute or obtain coupons, with the goal of ensuring that all patients who leave with prescriptions are able to fill them.

Some hospitals have “meds to beds” programs, especially for high-risk patients. These programs have local retail pharmacists bring medications directly to the patients before discharge. These hospitals report significant decreases in medication discrepancies.

**12. Make change visual.**

One hospital posts reminders in patient rooms about prevention techniques for common problems such as falls and pressure ulcers. Visual cues include a pressure scale and a whiteboard featuring a checklist of items staff and patients can check off daily. This fosters collaboration among staff, patients, and family caregivers as participants in ensuring patient safety. The patient and family advisory council participated in the development of the visual aids to ensure those receiving care and family caregivers can understand them easily.
Quantifying the Benefits

Benefits of Integrating Family Caregiver Support

For Organizations and Staff

- **Preventing discharge delays**—Instructing family caregivers helps hospital staff avoid discharge delays. Staff can provide and reinforce information gradually throughout the hospital stay rather than deliver large quantities of information to distracted family caregivers during the flurry of discharge activity. Staff can also better coordinate discharge scheduling when family caregivers understand the process and are prepared to arrive at the hospital at the time of discharge.

- **Streamlining staff communication with family members**—Family caregivers can relay information to other family members and friends, saving hospital staff the time and energy spent repeating the same information to multiple individuals. When families are uncertain about who is the most suitable person to serve as the primary family caregiver, offering time for families to come to consensus is helpful. Allowing extra time also helps when large families want to divide caregiving tasks among multiple individuals.

- **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 patient that signal a need for intervention and provide additional context that can affect decisions about care. 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.

- **Instructing the right person in postdischarge care**—By correctly identifying the person or people who will be helping at home, hospital staff can focus their efforts appropriately. It is vital to ask who will serve as the primary family caregiver because staff may not ever encounter that individual in the hospital room. It is also important to tell families that they should inform the hospital staff if someone else becomes the primary family caregiver.

For Families

- **Detecting complications early to prevent problems that can lead to readmissions**—Qualitative data indicate that discharged patients may be less likely to have a complication at home that interferes with their recovery or requires an emergency department visit or hospital readmission when staff across roles and shifts assess family caregivers and fully prepare them for the care they will be providing. When family caregivers understand how to identify a potential complication early, they can seek help before the problem requires treatment in the hospital setting.

- **Decreasing family caregiver emotional, practical, and financial strain**—Family caregivers who are adequately prepared to provide care at home can experience reduced strain and disruption of daily life during and after a family member’s hospital stay. They are better equipped to manage complex medical/nursing tasks and pain, which is a major issue that carries an emotional as well as practical and sometimes financial strain. When family caregivers understand what to do and expect and how to look for potential complications, they have increased confidence and attentiveness. Good preparation allows them to focus at home on providing emotional support to the care recipient and to address the impact of caregiving on their own health and well-being. Good preparation also gives care recipients confidence in the family caregivers.

- **Facilitating continuity of care**—A designated primary family caregiver with a good understanding of the care he or she will be providing at home can serve as the main point of contact to ensure continuity of care before, during, and after a hospital stay. The hospitalized individual may move to a skilled nursing or assisted-living facility or—more commonly—back home or to a family member’s home. Continuity of care during all transitions within and outside the hospital helps ensure medication reconciliation and accurate and complete communication of patient-specific details, including values and preferences, and prevents care and communication gaps, errors, and omissions.

- **Arranging appropriate support at home to foster a successful recovery**—By having early and ongoing conversations about care for the patient after discharge, staff and family caregivers can collaborate to determine what will be needed and arrange for adequate instructions, supplies, and equipment necessary to manage medical/nursing tasks at home and any further
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help that may be required. Staff can provide referrals to community resources that support the plan for postdischarge care.

- **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 at home. It is also 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.

**What Does Success Look 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 wasn’t universal identification of the direct link of family caregiver engagement with 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 to go home for the next phase of care.**

**Overcoming Perceived Barriers**

**Resolving Challenges in Making Practice and System Changes**

Hospital leaders identify obstacles to the change process and develop ways to overcome those barriers. Initial reactions to the provisions of the CARE Act by hospital leaders and staff during site interviews include concerns that ultimately diminish.

- **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.
  - **Resolution:** 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.

- **Challenge:** Discharge delays occur when family caregivers aren’t available for instruction.
  - **Resolution:** Provide instruction throughout the hospital stay. Set a mutually convenient time for instruction or arrange for home health to provide family caregiver instruction after discharge. Promote the option of ordering home health.

- **Challenge:** Some hospitals experience high turnover and new hires require training to understand the strategies, goals, and tactics of family caregiver guidance, support, and instruction.
  - **Resolution:** Modifying staff onboarding training is a short-term effort that becomes self-sustaining in the long term.

- **Challenge:** Some large health care systems operate in multiple states with differing requirements for family caregiver support.
  - **Resolution:** One health care system uses the broadest and most comprehensive approach across all locations. For example, it includes family caregivers of people on observation status, a group that may not be included in the CARE Act because observation status is an outpatient designation rather than the inpatient designation generally targeted by the CARE Act.
Additional Information

Implications of COVID-19

The COVID-19 pandemic has intensified the importance of identifying and engaging family caregivers. Strict visitor policies have hampered the ability of family caregivers to be part of the hospital experience and be available to support their family member and participate in care. Limited face-to-face interaction between hospital staff and family caregivers hinders communication about contextual details and decision support—creating challenges for staff members to maintain care quality and for family caregivers to obtain guidance and instruction on postdischarge care.

Innovations are emerging to foster communication and support caregivers in new ways through technology. The timely launch of the Supporting Family Caregivers Providing Complex Care publication series highlights a wide variety of promising practices in family caregiver support just when they are most urgently needed.

Helpful Resources

The CARE Act

The name of the law and its specific provisions vary by state, but CARE Act legislation generally requires that hospitals do the following to support family caregivers:

- Advise individuals in the hospital 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 on the medical/nursing tasks they will handle at home.

See the CARE Act map, which shows more than 40 states that have passed the legislation.

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.

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 handling incontinence. These resources, many of which are available in both English and Spanish, are free of charge to all. Visit aarp.org/nolongeralone.

Related Publications 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 founding partners of the Home Alone Alliance, a collaborative of AARP, and funded by The John A. Hartford Foundation.4

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.5,6

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.7

The National League for Nursing (NLN) offers simulation modules 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.
Additional Theme Papers in This Series

- **Learning Resources and Practices to Improve Patient and Family Engagement**: 12 Ways to Facilitate Family Caregiver Education in Hospitals (PDF)

- **Staff Training Practices to Improve Patient and Family Engagement**: 16 Ways to Include Family Caregivers and Prevent Discharge Delays (PDF)

- **Electronic Health Record (EHR) Practices to Improve Patient and Family Engagement**: 9 Ways to Help Staff Access Data on Family Caregiver Discharge Preparation (PDF)

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://states.aarp.org/tag/the-care-act](https://states.aarp.org/tag/the-care-act). To learn more about the Home Alone Alliance, visit [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone).

Series Authors

Authors of the Supporting Family Caregivers Providing Complex Care series of publications:

- Susan C. Reinhard, RN, PhD, FAAN, Senior Vice President and Chief Strategist, Nursing Workforce and Family Caregiving Initiatives, AARP Public Policy Institute. @susanpolicy

- Heather M. Young, RN, PhD, FAAN, Senior Fellow, AARP Public Policy Institute; Professor, Betty Irene Moore School of Nursing, University of California, Davis. @YoungHeatherM

- Rita B. Choula, MA, Director, Caregiving, AARP Public @rchoula

- Karen Drenkard, RN, PhD, FAAN, NEA-BC, Associate Dean, Clinical Practice and Community Engagement, The George Washington University School of Nursing. @DrDrenk

- Beth R. Suereth, Founder and Chief Executive Officer, Caregiving Pathways. @BethSuereth

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