Overview

Transitional care programs and support after hospital discharge have become more important aspects of care, reflecting today’s environment of value-based care and readmission penalties.

The transition from hospital care by trained professionals to care at home by family caregivers can be a critical time. Family caregivers—the people in the patient’s social support system who will help manage care at home after discharge—often are not equipped to provide care or recognize or manage complications on their own.

Hospital clinical leaders understand the need to instruct and support family caregivers throughout the hospital stay to prepare them to handle the medical/nursing tasks they face at home. This preparation promotes the fullest possible recovery of the person in their care.

Support after hospital discharge is also essential to answer family caregiver questions about unexpected situations and reinforce the knowledge they need to provide good care.

Hospitals facilitate successful discharges and follow-up care at home by family caregivers through approaches that include the following:

- Robust discharge planning engagement by nurses
- Enhanced social worker–nurse collaboration to plan the transition and anticipate needs
- Follow-up calls between hospital-based nurses and family caregivers at home
- Proactive connections to community resources

Staff also address social determinants of health that contribute to readmissions. They help family caregivers obtain and manage the medications, equipment, and supplies they need to provide care safely at home.

Some initiatives are a direct result of the CARE Act. Other supports were already in place and many were enhanced to achieve consistency across an organization.
Emerging Themes of the Supporting Family Caregivers Providing Complex Care Publication Series

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

Now more than ever, the health care continuum includes postdischarge care at home delivered by family or friends. Health care systems increasingly expect these family caregivers to continue implementing the care plan after discharge, delivering many types of care that experienced professionals provide in hospitals. More than 20 million family caregivers perform complex medical/nursing tasks at home after discharge and largely learn how to manage caregiving on their own.¹

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.

When Family Caregivers Are Unprepared

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.
Lack of Empowerment: A Vignette

The following example illustrates gaps in family caregiver preparation during a transition from hospital to home. The promising practices shared in this paper can help prevent those gaps.

Example: Carla is hospitalized with diabetes complications. When Lucas, her husband of 50 years, visits Carla, he feels like he is in the way when a nurse is in the room. Lucas is not aware of the medical/nursing tasks he will be responsible for when Carla gets home.

After several delays, the discharge planner calls Lucas to tell him Carla will be discharged in a few hours. When Lucas arrives, he thinks Carla is too ill to go home. He is scared, but he says nothing so he does not worry Carla.

At home, Lucas and Carla are overwhelmed by the many details of Carla’s physical therapy, wound care, pain management, medications, and meal preparation. When a nurse calls from the hospital two days later to see how Carla is doing, Lucas tells her only some of his concerns for fear of looking neglectful or ignorant. He is not even sure how to express his concern about not knowing what problems to look for and how to avert them. The next week, Carla falls after losing her balance because her foot wound is infected and painful and she is weakened from being in bed for so many days. Lucas calls an ambulance.

Repercussions: Carla went back to the hospital. Lucas felt he failed Carla. Lucas told a nurse that Carla needed more care than he could provide. The discharge planner recommended a stay at a rehabilitation facility, but Carla’s insurance did not cover it. Carla went home with Lucas, and they made the best of a difficult situation. Carla’s health declined and eventually she moved permanently to a skilled nursing facility. Carla and Lucas were separated and distraught.

Opportunity: Providing family caregiver support from admission through postdischarge helps patients get the level of care they need when it will do the most good rather than as a last resort. Nurses and social workers could assess family caregivers upon admission for ability, willingness, availability, and instructional needs. Staff could provide interactive guidance, instruction, and reinforcement to ensure family caregivers are prepared to deliver safe follow-up care after discharge. Postdischarge nursing calls could help family caregivers monitor progress, address barriers, and prevent complications. These supports can give family caregivers the confidence and competencies they need to provide good care safely at home.

Lucas could be prepared to look for warning signs of complications and have a nurse visit their home to provide care for Carla and teach Lucas how to perform medical/nursing tasks. He could feel empowered to ask all of his questions and take action before Carla develops a problem that could result in readmission or a cascade to dependence. Carla could recover and experience a much better quality of life for the rest of her life.

What Family Caregivers Need during the Transition to Home

During the discharge process, family caregivers are often hurried and focused on logistics. They need an opportunity outside of that rush to learn in depth about or reinforce the many details involved in the care, medication, equipment, and supplies they will manage at home.

Ideally, family caregiver preparation begins before or at admission and continues throughout the hospital stay, with multiple opportunities for staff to set expectations and provide guidance and instruction. This allows family caregivers to absorb information over time; observe the care they will ultimately deliver; and process and reflect on discussions, decisions, and what needs to be put in place at home. Ongoing discussions enable nurses to identify situations in which the person receiving care can benefit from having the family caregiver talk with a social worker and a nurse to address barriers related to social determinants of health. Addressing obstacles before discharge can help avert problems for patients, family caregivers, and hospitals after discharge.

With or without family caregiver preparation over the course of the hospital stay, it is important for nurses to sit down at
Transitions in Care and Hospital Discharge Practices to Improve Patient and Family Engagement

discharge with the family caregiver and the person receiving care for an unhurried, in-depth discussion to assess family caregiver readiness and understand and fill gaps. The family caregiver and the person receiving care get the opportunity to confirm their understanding of the care plan, ask clarifying questions, voice their fears, and troubleshoot how to overcome impediments—especially social and financial concerns that can get in the way of implementing the plan. They also get important information about resources in the community that can support them over time.

Preparation is especially important for family caregivers of high-risk patients who require significant medical/nursing support at home.

16 Highlighted Practices

How Hospitals Facilitate Family Caregiver Support during Transitions in Care and Postdischarge

Health care systems use various approaches to prepare family caregivers to provide effective and safe care at home. Highlighted practices from our ongoing national CARE Act implementation scan include the practices listed below.

Culture Change

1 Leading the charge

A culture shift is under way in many health systems and hospitals. To ensure family caregiver discharge readiness, health system leaders and front-line staff increasingly integrate family caregiver support into existing fundamental processes at every step of the hospital stay. Significant support from senior leaders is vital to the success of organizational culture change.

Drivers of this change include a better patient and family caregiver experience after discharge, better health outcomes at home with fewer complications and reduced readmissions, and better financial outcomes for hospitals—especially in light of the growing use of bundled payment structures.

2 Learning from patient and family advisory councils

Patient and family advisory councils increasingly influence hospital processes, particularly after the passage of the CARE Act. Hospital leaders listen closely to what these stakeholders report will best meet their needs.

Preadmission Practices

3 Educating family caregivers before admission

For scheduled procedures, some hospitals provide family caregiver education before the hospital stay. Preadmission guidance and education allow the family caregiver and the person receiving care to understand the role of the family caregiver after discharge and set expectations for all involved. Family caregivers get ample time to prepare for the medical/nursing tasks they face at home and can practice providing complex care under nursing supervision during the hospital stay. They can also learn about risk factors for and techniques to prevent common issues like pressure ulcers (bedsores), which are painful and can lead to serious infection.

Family caregivers learn what to expect so they can purchase equipment, supplies, and medications and have these items ready at home before the hospitalization even begins. This allows them to focus their attention during the hospital stay on learning about postdischarge care and providing emotional support to the person receiving care rather than hurriedly making preparations at the last minute and feeling overwhelmed and stressed.

One hospital fully integrates family caregivers into its joint surgery program, where surgeries are generally planned and payments are bundled. Family caregivers participate in meetings weeks before surgery, and they are present during the hospital stay for clinical rounds, physical therapy sessions, and dressing changes. They can even stay overnight in the hospital after surgery. Family caregivers become familiar with every aspect of the process, including staff, group exercise classes, and various aspects of care coordination. This deep level of involvement helps increase discharges to home instead of a rehabilitation facility and ease anxiety for those receiving care and for family caregivers.
Discharge Practices

4 Screening family caregivers at admission
Some health systems begin discharge planning upon hospital admission by screening for postdischarge needs, then scheduling a family caregiver care conference.

5 Tailoring discharge instructions for diverse populations
Because family caregivers are so diverse, 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.

6 Enhancing coordination among staff in different roles
Case managers or social workers have traditionally communicated with family caregivers. The focus has been on logistics of care transitions, such as understanding insurance coverage and finding home care assistance or availability in a rehabilitation, skilled nursing, or assisted-living facility.

Hospitals increasingly integrate logistical and clinical support through collaboration between social workers and nurses because family caregivers are dealing with complex medical/nursing tasks. For some hospitals, it is a matter of standardizing existing practices. Others implement changes to meet the requirements of the CARE Act. All aim to assist the person receiving care and the family caregiver in any way that supports a successful recovery at home.

When nurses and social workers collaborate closely, they can more easily anticipate and identify needs and barriers as they plan and implement a successful transition. This collaboration is vital when a social worker or nurse asks the person receiving care, “Is there someone who will help you at home?” and the answer is no.

Here are some examples of how collaborations across roles are organized at various hospitals:

- A discharge planner and a nurse become a long-term dyad and together meet with each family within 24 hours of admission.
- Case managers communicate with nurses, patients, and family caregivers to identify barriers to safe, effective care at home.
- Case managers coordinate with nurses and other hospital staff in various areas, such as wound care, physical therapy, and the pharmacy. They use information in the EHR on family caregiver readiness to identify risks for readmission.

7 Creating new roles and reorganizing responsibilities
Hospitals are creating new roles and changing processes and workflows to educate and support family caregivers. Here are some examples of these types of practices:

- Hospitals employ patient logistics practitioners (PLPs), a role that combines the functions of registered nurses, case managers, and utilization reviewers. PLPs prepare patients for discharge. They may also be responsible for identifying family caregivers, notifying them about discharge timing, and preparing them for postdischarge care.

- PLPs are the primary educators for patients and family caregivers, using teach-back and other techniques to ensure family caregiver understanding. Often, PLPs provide patient and family caregiver education at home after discharge. Hospitals develop training programs for registered nurses to become PLPs.

- Case coordinators serve as liaisons to the emergency department to direct patients to a skilled nursing facility when appropriate to avoid an unnecessary readmission.

- Nurse practitioners manage patients and discharge planning, gather information from staff across roles, and update family caregivers daily. This approach was pioneered by Dr. Mary Naylor and her team.
Providing medications for home use or prescriptions before discharge

Health care leaders recognize the value of having medications on hand when patients arrive at home. This prevents having the person receiving care be left home alone while the family caregiver goes to a pharmacy to fill prescriptions.

Several health systems have programs that deliver medications to the bedside or home before the day of discharge. Some provide prescriptions before discharge to enable family caregivers to obtain medications in advance. Pharmacists at many hospitals educate family caregivers about medication management and barriers to compliance. Some pharmacists coordinate with the family caregiver’s local retail pharmacist.

For additional details, see Pharmacy Innovations to Improve Patient and Family Engagement: 10 Ways Hospitals Help Family Caregivers Prepare to Manage Medications in this publication series.

Establishing a robust transition suite staffed by nurses

Hospitals are creating separate transition suites where full-time dedicated nurses give family caregivers the unhurried focused attention they need to fully understand and prepare for their postdischarge responsibilities. These suites are not to be confused with the ineffective discharge lounges of the past that functioned largely as patient waiting areas.

Transition suites provide a safe place for patients and family caregivers—especially those dealing with a high-risk situation—to get a range of non-inpatient supports that will help them carry out the care plan, feel safe at home, and alleviate their concerns and anxiety. Family caregivers have the opportunity to practice the medical/nursing tasks they will perform at home and get help finding the medications they need at affordable prices. After discharge, transition suite nurses make follow-up calls and review discharge information, confirm family caregiver understanding, and answer questions.

Many changes related to the transition suite result from the passage of the CARE Act and internal auditing to ensure alignment with its tenets.

Documenting family caregiver readiness in the EHR

Several health systems customize their EHR to include information about family caregivers and document their preparation for discharge. Staff at many hospitals recommend enabling a dashboard of family caregiver readiness with a cross-discipline view that allows clinicians to enter and update specific family caregiver information (rather than just check boxes) at any time. Visualization tools would display relevant information about the status of family caregiver preparation for discharge in a concise and cohesive manner, bringing together information from many existing EHR fields. These tools would also enable each care team member to readily understand staff roles in filling any gaps.

For additional details, 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.

Providing inpatient rehabilitation apartments for family caregivers

One hospital features apartments where the person receiving care and the family caregiver can stay for 48 hours prior to discharge. They practice living with the new situation with the assurance of knowing staff are nearby if they have questions or difficulties.

Connecting family caregivers with community resources

Some health systems integrate existing social support organizations into their business structure to help the community members they serve achieve good mental and physical health. Such integration can enable easy sharing of patient and family caregiver information among medical and social service providers through the EHR.

Some hospitals develop long-term relationships with staff at community organizations and collaborate with them. They work on an ongoing basis with community resource staff to support family caregivers and those they care for. The case management department at
Transitions in Care and Hospital Discharge Practices to Improve Patient and Family Engagement

one hospital uses its deep connections to community resources to proactively assess the physical home environment and locate friends and neighbors who can provide assistance.

Hospitals also actively encourage family caregivers to attend community-based support groups, such as those for people who have a specific condition. Staff member encouragement holds a lot of weight.

13 **Arranging home visits by nurses, social workers, and case managers**

Some hospitals have discovered that even when family caregivers seem to understand what to do, they often go home and are so overwhelmed that they forget what they learned. These hospitals frequently arrange for a home care nurse to provide instruction on the first or second day after discharge on how to handle medical/nursing tasks effectively and safely. Health insurance often covers home health nursing visits.

In some circumstances, hospitals arrange for a social worker or case manager to make a home visit after discharge, sometimes in addition to the clinical support. One hospital with good nearby community resources covers the cost of case managers who make home visits to provide navigational support. A similar program at another hospital is funded by a volunteer association that supports the hospital.

14 **Taking inbound calls**

Some health systems have call centers staffed by nurses who answer questions from those receiving care and family caregivers. Some call centers are available for the family caregiver to call day or night. Staff taking the calls note that family caregivers are more comfortable calling after discharge than asking questions during the hospital stay.

One health system has a family caregiver hotline that it promotes through nurse recommendations and notecards in patient rooms. The hotline is available during hospitalization and after discharge. Callers leave a message and receive a response within 24 hours, and they are welcome to use up to an hour of live support per week. Hospital staff note the hotline as a best practice. The system created the hotline to respond to questions about the CARE Act, but family caregivers use it to ask caregiving questions.

At another health system, people receiving cancer care and their family caregivers have a 24-hour hotline to call after discharge. Staff there recommend creating an additional hotline for noncancer care.

Some hospitals write the contact information for the floor nurses on the discharge paperwork so family caregivers can call the unit where they received care. Some nurses, though, are reluctant to give advice to a patient whose case they do not know. On the bone marrow unit at one hospital, family caregivers can call the charge nurse directly since speed of response can make a significant difference for those patients.

15 **Making outbound calls**

Staff at many hospitals make one or more follow-up calls to the home, one to three days after discharge. They review medications, address issues, place orders for equipment, and give encouragement and advice. Often they talk with a family caregiver instead of or in addition to the person receiving care, who may be asleep, in pain, or otherwise recuperating and not in a frame of mind to ask the right questions or provide appropriate context.

Different hospitals have staff in different roles place calls to care recipients and families:

- Nurses from units, retired nurses hired for this purpose, call center nurses specializing in transition support or from the unit from which the person receiving care was discharged
- Pharmacists—some provide only follow-up care
- Case managers, social workers, patient advocates, and volunteers

Check-ins by clinical staff help family caregivers as they become skilled at performing medical/nursing tasks at home. Nonclinical calls provide navigational support. Some hospitals provide the staff making the calls with consistent framing, content, and language.

Some hospitals have varied calling programs. One calls 90 percent of patients and reaches 80 percent. Other hospitals call only those people receiving care in certain service lines, such as orthopedics or cardiac care. Some hospitals use automated calls for some patients and customized calls for high-risk patients. Others customize calls for certain specialized service lines.
One hospital established a call center to call every patient’s home after discharge and track all issues as part of its CARE Act implementation. The most common issues relate to medications and arranging support services at home.

One health system has a large person-centered medical home program for people with the most severe chronic conditions. Family caregivers receive calls to check on progress.

One health system uses a phone discharge program that integrates with case management to connect inpatient and outpatient care and services. Staff talk with family caregivers whenever possible and refer calls to appropriate professionals for further education and follow-up. The program manager attends patient care services meetings with nurse managers and leadership and provides regular reports to staff who participate in the program. They track trends and identify additional opportunities to provide family caregiver support. Nurses and case managers can simply click on a patient’s record to see what family caregivers were taught. Staff report that the program is very successful.

Another health system has an outpatient care management program involving a community care network that provides a range of no-cost supports aimed at reducing hospitalizations of high-risk patients. They also have a family caregiver support program in skilled nursing facilities.

One health system provides a patient summary to the person receiving care and transmits additional details to physician offices to support its meaningful use efforts. The hospital sends a transfer packet with patients who transition to skilled nursing facilities.

### Coordinating inpatient care and outpatient support

One health system uses a phone discharge program that integrates with case management to connect inpatient and outpatient care and services. Staff talk with family caregivers whenever possible and refer calls to appropriate professionals for further education and follow-up. The program manager attends patient care services meetings with nurse managers and leadership and provides regular reports to staff who participate in the program. They track trends and identify additional opportunities to provide family caregiver support. Nurses and case managers can simply click on a patient’s record to see what family caregivers were taught. Staff report that the program is very successful.

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### Quantifying the Benefits

**Benefits of Transitional and Postdischarge Support for Family Caregivers**

**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 let families know 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.3 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 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 was not 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 Implementing Family Caregiver Support during Transitions in Care and Postdischarge

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:** Hospitals must decide how to begin making changes to longstanding 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:** Discharge information is voluminous and overwhelming.

**Resolutions:** Use simplified language, graphics, and formats. 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:** Family caregivers rarely attend support groups because they are too busy.

**Resolution:** Provide emotional support during and in addition to ongoing one-to-one instruction in the hospital and through community resources 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:** Fiscal planning that takes into account the costs of not providing this support can promote the funding of services and supports that offset costs in other areas of the budget, such as unreimbursed readmissions.

**Challenge:** Documentation of family caregiver education is limited and dispersed across the EHR.

**Resolution:** Work with the EHR provider or internal information technology team to reconfigure the display of family caregiver data, assessment of readiness, and instruction into a more easily accessible, single view to enable enhanced interactions with family caregivers.

Additional Information

Implications of COVID-19

The COVID-19 (severe acute respiratory syndrome coronavirus 2) 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 AllianceSM, 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 (A/N) publishes award-winning evidence-based, peer-reviewed articles and videos that teach clinicians how to best support family caregivers. AIN 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 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. For more information about the CARE Act, visit the AARP Public Policy Institute website or https://states.aarp.org/tag/the-care-act. To learn more about the Home Alone Alliance, visit www.aarp.org/nolongeralone.
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3-5 Reinhard et al., Home Alone Revisited.