COMMUNICATION PRACTICES TO IMPROVE PATIENT AND FAMILY ENGAGEMENT:
10 WAYS TO IDENTIFY AND ENGAGE FAMILY CAREGIVERS IN HOSPITALS

Overview

Communication is at the core of successful care coordination and collaboration with family caregivers—the people in the patient’s social support system who will help manage care at home after discharge from the hospital.

Health care systems identify and engage family caregivers to achieve the following benefits:

- Enhance inpatient care plans and outcomes through collaboration.
- Prevent discharge delays and readmissions by preparing family caregivers to safely perform medical/nursing tasks and detect early signs of complications.
- Decrease family caregiver emotional, practical, and financial strain.

Instructing family members who will perform medical/nursing tasks after a hospital discharge is sound policy that’s good for business. Involving family caregivers during the hospital stay reflects a commitment to person- and family-centered care and improves outcomes for all people, regardless of their age or diagnosis, and to the family members, neighbors, and friends who support them.

Health care systems increasingly expect family caregivers, who are often unprepared, to perform complex care after a family member or friend is discharged from the hospital. Providing family caregivers with instruction and guidance throughout the hospital stay can significantly help them manage the individual’s ongoing comfort and quality of life and prevent complications at home that can lead to emergency department visits and readmissions.

Hospitals enhance their communication processes with these critical members of the care team in many ways. The first step is to recognize and value family caregivers as integral members of the health care team who should...
be included in planning and prepared for this phase of their caregiving journey. The process starts with identifying who should be included in care coordination discussions as a family caregiver.

**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**

As health systems increase expectations for family caregiver participation at home after discharge, the need for family caregiver preparation increases. That preparation includes communication between clinicians and family caregivers throughout the hospital stay.

Hospital leaders see the need to develop new practices for communicating the complex information family caregivers need to safely provide follow-up care at home. Family caregivers need to acquire information that previously fell within the purview of health care professionals. This information includes understanding the purpose of a specific task, the proper procedures for performing the task, potential complications or side effects to look for, what may happen if the task is not performed, and when and whom to call for help. Some tasks require special supplies or equipment, and all require focused attention.¹
Communication Gaps: A Vignette

The example below illustrates common gaps in communication between clinicians and family caregivers, subsequent consequences, and opportunities for system change. The promising practices shared in this paper can help prevent those gaps.

Example: Daniel has multiple conditions, including mild cognitive impairment. He is hospitalized for shortness of breath associated with his congestive heart failure. His wife, Florence, is exhausted from caring for him at home and is upset that he had to go to the hospital again. While Florence is out of the room, the pharmacist comes by to give Daniel instructions about new medications, how to record his symptoms, and what changes to report. The pharmacist isn’t aware of Daniel’s cognitive impairment. During the discharge process, a nurse gives Florence information about picking up a new digital scale and blood pressure cuff. The nurse also instructs Florence to record Daniel’s vital signs and weight daily and to call if he experiences certain symptoms. Florence waits for hours for his prescription medications and oxygen supply.

Once they get home, Florence helps Daniel to his chair. The exertion of the trip home has tired him out, and he is very short of breath and anxious. Florence checks the instructions she received and notices the medications are different from those he had previously been prescribed. She isn’t sure whether she should give him his usual medications along with the new ones. Daniel can’t remember what the hospital pharmacist said. The oxygen company is scheduled to come by later that day, but Florence is not sure when and Daniel’s supply is low. Florence decides to continue giving Daniel his previous medications until they see his doctor the next week. Over the next day, Daniel has more difficulty breathing, his ankles swell, and he is very anxious. Florence is worried and takes him back to the hospital.

Repercussions: Daniel was readmitted and Florence was distraught. She feels she is on a rollercoaster and is losing confidence in her ability to care for Daniel.

Opportunity: The hospital could establish processes to identify caregivers and assess how willing, able, and prepared they are to provide care at home. Family caregivers like Florence are already overwhelmed and could benefit from additional supports to bolster their ability to provide care.

An interprofessional team approach would contribute to more comprehensive management of the many issues that families are managing. The staff would communicate better with one another about the treatment plan and include family caregivers like Florence in the planning as well as provide hands-on instruction. Having more family caregiver support in the hospital and better support for the transition home would create a better experience for Daniel and Florence and help prevent readmissions.

The Importance of Identifying the Family Caregiver

Half of family caregivers in the United States—20 million people—perform complex medical/nursing tasks, including, but not limited to, the following:

- Administration and management of medications, including pills, eye drops, suppositories, and injections
- Care for wounds and ostomies to enhance healing and prevent infection
- Insertion of catheters to assist with urinary elimination
- Operation of specialized medical equipment and devices
- Assistance with mobility challenges
- Preparation of special diets with strict requirements and new foods
- Management of prolonged or intense pain

Many family caregivers do not receive instruction on how to perform the medical/nursing tasks they are expected to manage at home. It is critical for family caregivers to have the information they need to provide that care safely—to
help promote good health outcomes and help prevent complications and hospital readmissions. Preparation for managing complex care at home includes anticipating not only the practical aspects but also the emotional and financial strain.

People who are hospitalized may identify one or more of these individuals as a family caregiver:
- Family member
- Life partner
- Friend
- Neighbor

Under many circumstances, when 24-hour care is required, an individual relies on several family caregivers to rotate shifts. Once active family caregivers are identified, hospital staff can assess their readiness and prepare them to provide the complex care required after discharge.

Family caregivers often are not aware of signs of normal healing compared with symptoms of abnormal changes that require professional attention. Many family caregivers worry about making a mistake, which only adds to the strain they experience in providing care. Those who worry about making a mistake often feel they have to be vigilant; compared with other family caregivers, those who worry about making a mistake find caregiving tasks to be more difficult. Health care professionals can make a difference in preparing family caregivers for both the procedural and emotional aspects of assuming the responsibility of medical/nursing tasks.

More and/or better instruction is the most common response from family caregivers when asked what would make it easier to perform medical/nursing tasks at home. Preferred instruction formats include additional exposure to the content, practice with supervision, written instructions, visual instruction, videos, consistency in instructions, and a phone number to call with questions.

Family caregivers need instruction on the following:
- How to perform medical/nursing tasks
- Side effects to watch for
- Indications of improvement and recovery
- The first signs of potential complications
- Using devices and equipment
- When and whom to call for help and information

**Differences among Family Caregivers That Affect Their Capabilities**

While discharge instructions can be viewed as “tasks,” they also carry meaning for family caregivers in terms of worry about performing the task and the implications for their daily routine. Just as caregivers are diverse, interventions to meet their needs for support and guidance must be varied and flexible.

Some family caregivers have physical limitations or cognitive decline that interferes with their ability to provide care at home. Many are working and balancing competing demands. Others have low health literacy and have difficulty understanding technical written instructions.

Some family caregivers are less comfortable or adept than others when faced with using technology, equipment, and devices at home. As a result, they may require more training.

One in four family caregivers who perform medical/nursing tasks is a millennial, and this group generally worries more than older generations about making a mistake in providing care. Multicultural family caregivers are more likely than others to experience strain and worry about making a mistake, regardless of income.

Men report they struggle more with certain tasks—such as managing pain, helping with incontinence, and preparing special diets—and are more likely to indicate that receiving additional instruction at home would help them. It’s important to note that, when their family member is hospitalized, men are less likely to receive instruction on how to perform complex tasks after discharge.
10 Highlighted Practices

Communication Enhancements to Workflows

Hospitals improve existing workflows in many ways to facilitate communication among family caregivers and hospital staff (with patient permission). These enhancements span the entire hospital stay and diverse family caregiving situations. The top communication practices from our ongoing national CARE Act implementation scan include the activities listed below.

In addition to facilitating communication between clinicians and family caregivers, many of these enhancements also facilitate communication among clinicians across different roles and shifts.

1. **Asking “Who will help at home after discharge?”**
   Staff document family caregiver contact information, readiness, instruction received, and knowledge gaps and explain to all involved why it is important for family caregivers to be included in care discussions and receive instruction.

2. **Using the teach-back method during routine bedside care**
   to ensure family caregivers understand instructions, can repeat back what they’ve learned, and receive feedback—so they have confidence in providing care at home.

3. **Providing name tags for family caregivers**
   to help nursing staff identify the individual(s) they should instruct in postdischarge care.

4. **Adding the names of family caregivers on white boards in the hospital room**—and perhaps other details, such as contact information, goals of care, and expected discharge date—so that all staff are aware of the caregivers, which can facilitate clear communication among all involved. In some hospitals, family caregivers are encouraged to write questions or comments on the white board.

5. **Including family caregivers in shift changes**
   as a means of providing a status update and an opportunity for a family caregiver to provide relevant information, ask questions, demonstrate understanding, and participate in decision making; using the patient motto “nothing about me without me”

6. **Initiating team huddles**
   to facilitate discussions among multiple types of stakeholders, including family caregivers.

7. **Fostering interdisciplinary rounds**
   that include the family caregiver and enable consulting specialists to coordinate decision making.

8. **Facilitating postdischarge communication,**
   such as follow-up phone calls soon after discharge, so family caregivers can obtain reinforced instruction and ask questions after they get home to help prevent complications and readmissions. Some hospitals also use the information they gather in those calls for ongoing quality improvement in preparing for discharge.

9. **Introducing family caregivers to postdischarge resources,**
   with hospital staff conducting warm hand-offs.

10. **Telling family caregivers how to prevent specific complications,**
    which increases family caregiver confidence and attentiveness.
Getting Started: Communication Processes and Ownership

As hospitals transition to person- and family-centered care, enhancements to workflows begin with setting the tone in communication for collaborating with family caregivers and using the EHR as the foundational structure for standardizing ongoing interactions and communications among staff.

Establishing Ownership

It is critical to communicate at the outset which group of hospital stakeholders is responsible for preparing family caregivers to provide postdischarge care. This helps all involved understand their roles and individual accountabilities in identifying family caregivers, documenting their contact information, and including them in care management throughout the hospital stay.

Identifying and documenting family caregivers should not be the responsibility of a single individual. Staff in at least two different roles should share responsibility to ensure identification takes place either upon admission or shortly thereafter. Some hospitals train registrars and emergency department staff to enter family caregiver information into the EHR at intake and train admissions and nursing staff to differentiate among the 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 helps prevent staff from providing information to someone who should not have access to it.

Determining Roles and Responsibilities

While everyone in the hospital who interacts with family caregivers helps establish positive collaboration and communication, it’s vital to ensure that all team members understand their role. Promising practices indicate the clear value of taking steps like these:

- Determine which staff members will do the following:
  - Ask who will help at home after discharge.
  - Document this choice.
  - Explain to all involved why it is important for family caregivers to be included in care discussions and receive instruction.
- The next step is for these staff members to welcome each family caregiver to the team and explain how the hospital staff will interact with each individual during the hospital stay. Continuing communication and building rapport with family caregivers, especially the individual serving as the primary family caregiver, throughout the hospital stay helps ensure discharge readiness and successful care delivery at home.

- The backdrop of that communication should include staff actively seeking information about the goals, values, fears, and preferences of the person receiving care to ensure that the care plan is holistic and accounts for those factors. Addressing these aspects throughout the hospital stay helps set expectations for staff and families for promoting a successful outcome given the circumstances.
- In parallel, all members of the care team should document key data points in the EHR, enabling all involved to access family caregiver information throughout the hospital stay to facilitate care coordination. These data points include the following:
  - Family caregiver name and relationship to the patient (if more than one caregiver, indicate which individual will serve as the primary point of contact)
  - Contact information
  - Assessment and level of readiness of each family caregiver named
  - Remaining knowledge gaps and actions to address those gaps

Quantifying the Benefits

Benefits of Identifying and Including Family Caregivers

For Staff

- **Preventing discharge delays**—Identifying family caregivers helps hospital staff avoid discharge delays. Staff can provide and reinforce instructions gradually throughout the hospital stay rather than deliver large quantities of information to distracted family caregivers during the flurry of discharge activity. They can also better coordinate discharge scheduling.

- **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.

- **Taking advantage of the knowledge family caregivers have about the person receiving care**—Family caregivers can share relevant details about the hospitalized person’s goals, values, fears, preferences, and responses to treatment. They can also recognize subtle changes 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 members 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.\(^\text{10}\)

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 improve their own health and well-being. And a confident family caregiver increases the confidence level and emotional comfort of the person receiving care.

- **Facilitating continuity of care**—Designated primary family caregivers with a good understanding of the care they 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 individual 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 Communication Practices

In a cohort of hospitals across the country, leaders identify obstacles to the change process and ways to overcome them. Initial reactions to the provisions of the CARE Act by hospital leaders and staff during site interviews include four primary concerns that ultimately diminish:

**Challenge:** Lack of necessity—“We already do what the CARE Act requires.”

**Resolution:** Attention to the requirements of the CARE Act helps hospitals recognize the need to standardize their identification of and interactions with family caregivers. Initial concerns diminish when clinicians hear poignant personal stories about the existing gap between the information family caregivers typically 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.11

**Challenge:** Flexibility—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.

**Challenge:** Liability—Hospitals are concerned about creating Health Insurance Portability and Accountability Act (HIPAA) issues and the hospital being perceived as bearing responsibility for the health or well-being of family caregivers as well as negative outcomes at home.

**Resolution:** By more closely examining the provisions of HIPAA, hospitals clarify that, with patient permission, inclusion of family caregivers does not pose a legal risk.

**Challenge:** Delay of discharge—Operationally, discharge can be delayed when a family caregiver and staff are unable to coordinate schedules for instruction. People considered unsafe to discharge because the primary family caregiver is not ready or able to provide care at home may unnecessarily remain at the hospital for additional days.

**Resolution:** Successful organizations prepare staff to begin the process of discharge planning at admission, are flexible in the timing of instruction, and communicate clearly to family caregivers about the planned discharge date and time.
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 Alliance™, a collaborative of AARP, and funded by The John A. Hartford Foundation. 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. 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 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.
Communication Practices to Improve Patient and Family Engagement

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.

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 Policy Institute. @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

2-10 Ibid.
12,13 Susan C. Reinhard et al., Home Alone Revisited.