

PHARMACY INNOVATIONS TO IMPROVE PATIENT AND FAMILY ENGAGEMENT:

10 WAYS HOSPITALS HELP FAMILY CAREGIVERS PREPARE TO MANAGE MEDICATIONS

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.

Overview

More than 26 million family caregivers in the United States perform medical/nursing tasks for a family member or friend—an increase of nearly 5 million from 2014 to 2019.^{1,2} Eighty-two percent of these family caregivers manage medications.³ These data do not include the unknowable but enormous number of family caregivers managing short- and long-term care needs related to COVID-19 (severe acute respiratory syndrome coronavirus 2).

Managing medications is the task these family caregivers perform most frequently.⁴ They must understand, purchase, organize, and administer prescription and over-the-counter medications in forms such as pills, eye drops, suppositories, patches, ointments, inhalers, and injections.

More than half of these family caregivers do not receive instruction about the medications they are expected to manage at home.⁵ More and/or better instruction is the most common response from family caregivers when asked what would make it easier for them to manage medications.⁶

Hospitals increasingly innovate to provide such instruction to support family caregivers and prevent complications that result in the readmission of those receiving care.

Hospitals report making changes that include the following:

- **Providing patients with a supply of medication to take home at discharge**
- **Scheduling hospital-based pharmacists to meet with patients and family caregivers to reconcile pre- and posthospitalization medications**
- **Establishing discharge suites where nurses review medications and affordability with families**
- **Making follow-up calls to answer questions and resolve issues**

This paper shares promising pharmacy innovations that help family caregivers and those receiving care with the complex and stressful details of managing medications.

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 (ACOs), 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.

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

➔ Pharmacy innovations

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

The Need

More than Half of Family Caregivers Do Not Receive Instruction in the Hospital

Medications are a significant element of any hospital discharge plan, and family caregivers need specific guidance on how to manage them. Good medication management at home can be the most critical aspect of recovery for the person receiving care. If not monitored appropriately and administered correctly, some medications can cause devastating complications that can adversely affect the care recipient's quality of life for an extended time or through the end of life.

Lack of family caregiver preparation can lead to complications that bring decline and intense pain for the person receiving care. It can also generate family stress and upheaval when a complication triggers an emergency department visit, readmission, cascade to dependency, financial devastation, nursing home placement, or death.

Yet more than half of family caregivers report that they do not receive instruction in the hospital about the medications they are expected to manage at home; they learn on their own.⁷

Medication management is often complex and time consuming.

- Family caregivers must administer the right medication in the right dose at the right time. With many medication regimens, family caregivers give medications every day of the week, up to six times a day, and sometimes during the night, for years.
- Nurses who are also family caregivers report that even with their clinical knowledge and experience, they can find it challenging to manage a family member's medications at home.
- Nearly half of adults between the ages of 70 and 79 take 5 or more prescription medications; an additional 10 to 20 percent take 10 or more.⁸
- Those who take many medications—especially older adults and those without a good understanding of why they are taking each medication—may fare better by reducing the number of medications they take.
 - People can become overmedicated when they see multiple health care providers and/or use multiple pharmacies and can inadvertently end up taking medications with different names but the same active ingredients.
 - An individual can end up taking a new medication to address what is actually a side effect of another medication—but is mistaken for a symptom of a new or existing condition.
 - Issues with an ongoing medication regimen can arise as adults grow older. Toxicity due to metabolizing medications differently can occur. Sometimes stopping a medication is needed because the risks begin to outweigh the benefits.

The Instruction Family Caregivers Need Is Not Available Outside the Hospital

Managing medications today requires skills previously held by health care professionals, including an understanding of the purpose of the medication, the proper procedures in administering the medication, indications of complications or adverse side effects, and when and who to call for help. Some of the medications require special supplies or equipment, and all require focused attention.

Family caregivers need instruction from professionals during the hospital stay because there is no other way for

them to get detailed, nuanced information tailored to the specific situation of the care recipient.

The top two medication issues that family caregivers report are fear of making a mistake and the constant need to focus their attention on managing and administering medications.⁹ Fear of making a mistake comes in part from lack of understanding of the medication regimen. To ensure understanding, family caregivers need multiple learning opportunities throughout the hospital stay to hear instructions, repeat back what they've learned, and receive feedback (the teach-back instructional method). The more numerous and complex the medications, the greater the need.

Diverse Family Caregivers Face Varying Challenges

Family caregivers are culturally diverse, multigenerational, and gender inclusive. Accordingly, interventions to meet family caregiver needs for support and guidance must be diverse and flexible.

- When a family member is hospitalized, men are less likely than women to receive instruction on how to perform complex tasks such as medication management after discharge. Men report that they struggle more with certain tasks, such as managing pain.¹⁰
- Multicultural family caregivers are more likely to experience strain and worry about making a mistake, regardless of income.¹¹
- Caregivers with incomes below \$25,000 report greater difficulty managing medications and other medical/nursing tasks than those with higher incomes.¹²
- Different age cohorts face distinct challenges for their life stage.
 - Twenty-five percent of caregivers are millennials, and 40 percent of millennials and younger caregivers are supporting someone with a behavioral health condition. These younger generations of family caregivers experience almost twice as much difficulty managing medications as older generations.¹³
 - More older family caregivers indicate they have no choice in taking on medical/nursing tasks like managing medications compared with younger generations of family caregivers.¹⁴

Pain Medications Can Be Hard to Obtain and Require Constant Monitoring

Seventy percent of family caregivers face the practical and emotional strain of managing pain.¹⁵

Pain medications are especially challenging for family caregivers to manage. Family caregivers typically are not aware they can request a pain management or palliative care consult. They do not know the questions to ask or strategies for getting and using effective pain medications. Health care and social service professionals often do not address pain management in detail or elicit and respond to the worries of family caregivers.

Concerns about the overprescribing of opioids have led to difficulties in obtaining adequate pain relief, particularly for people whose chronic pain is managed with high levels of opioids. Twenty-one percent of men and 14 percent of women experience difficulty getting prescriptions for pain medications. About 2 in 10 generation X, millennial, and younger adult caregivers experience difficulty getting prescriptions for pain medications, compared with fewer than 1 in 10 of the silent generation.¹⁶

Pain medication requires constant monitoring and frequent adjustments, making pain an ongoing unpleasant focus and adding to the stressful feeling of the loss of control for both the person receiving care and the family caregiver. More men than women report difficulties and worry relative to pain medications. Twenty-two percent of men and 16 percent of women worry about giving a family member too little medication. Thirty-one percent of men and 25 percent of women worry about giving too much medication.¹⁷

Additional Challenges Impede Successful Medication Management at Home

Multidimensional challenges to medication management include the following:

- When family caregivers do not understand the need for a medication, they may be less likely to ensure adherence to it; they should be made aware of what may happen if a medication is not given.
- When the people receiving care are unable to manage their own medications because of illness, injury, dementia, depression, or a cognitive impairment, it is especially important for family caregivers to understand the medication regimen.
- Affordability and transportation to a retail pharmacy or the home of the person receiving care are common barriers for family caregivers.
- Family caregivers need help understanding myriad details that can affect health outcomes:
 - What time they should administer once-a-day medications. For example, family caregivers need to be aware that medications that may interfere with sleep should be taken during the day while those that cause drowsiness should be taken in the evening. Some medications should be taken with meals.
 - How to administer medications with conflicting instructions. An example is two medications that need to be taken at the same time of day, but one requires an empty stomach and one must be taken with food.
 - How to minimize medication side effects. For example, a medication that can cause lightheadedness, weakness, or insomnia increases the risk of a fall.
 - When they can and cannot split pills to save on medication costs. Some pills do not work the same way if they are split.
 - The effects of over-the-counter medications and supplements. Some may affect how certain prescription medications work.

Practical Obstacles: A Vignette

The following example illustrates some of the issues family caregivers face when managing medications at home after discharge. The promising practices shared in this paper can help address those issues.



Example: Isaac picks up his sister, Jasmine, at the hospital. Jasmine fell recently and injured her shoulder. She has dementia and often experiences additional confusion toward the end of the day. The discharge process is slow, and Isaac worries that Jasmine's dinnertime will be delayed. When her routine is interrupted, she sometimes will not eat, which triggers anxiety, diabetes-related issues, and medication refusal. In a hurry to get Jasmine home in time for her 6:00 p.m. dinner hour, Isaac is distracted about getting out of the hospital and rushes the nurse's explanation of Jasmine's new medications.

At home, Jasmine will not eat dinner, so Isaac does not give her a medication that must be taken with food. Jasmine agrees to take only two of her four other previously prescribed routine medications. Isaac leaves Jasmine home alone while he takes a bus to two pharmacies because the first pharmacy does not have the new pain medication in the strength and form prescribed by the doctor at the hospital. Neither Isaac nor Jasmine can afford the price of the medication. Isaac calls their brother, who reluctantly pays the pharmacy over the phone.

When Isaac gets home, Jasmine is in excruciating pain from a fall in the bathroom. He gets her to bed and gives her the pain medication as he tries to calm her down. Jasmine is in pain throughout the night. Isaac is not sure if it is because Jasmine's pain medication is not working, she was injured when she fell, her medication regimen has been interrupted, or she has not eaten enough. Isaac looks at the discharge instructions, but they are long and hard to understand.

Isaac is so desperate to help Jasmine that during the night he gives her more than the prescribed dose of

pain medication, fervently hoping nothing bad will happen as a result. He does not know who to call for help but decides to call her primary care doctor. It is a Saturday, so the office is not open; he is told to take Jasmine to the emergency department at the hospital for an evaluation. It takes Isaac an hour to coax tired Jasmine out into the rain to get the bus.



Repercussions: Jasmine was readmitted to the hospital with increased confusion and pain and a dangerous blood sugar level. Isaac felt inadequate and resentful because he missed an additional day of work.



Opportunity: The hospital could provide a supply of medication at discharge so Isaac would not need to leave Jasmine alone to go to the pharmacy, and Jasmine's pain would not spike, rendering it harder to control. The hospital could provide instruction throughout the hospital stay to prepare Isaac to handle common scenarios that could result from Jasmine's specific circumstances. A hospital pharmacist could counsel Isaac on the nuances and dangers of obtaining and administering opiate pain medications. A prescriber could ensure a home evaluation by writing an order in the hospital for home health support and a visiting nurse referral.

Isaac would be prepared to understand whether the pain medication was working and would have a phone number to call with questions, even in the middle of the night. He would feel empowered to take action and respond appropriately before Jasmine develops a problem that results in readmission. Isaac and Jasmine would have a better experience and less disruption of their lives.

10 Highlighted Practices

Ways Hospitals Equip Family Caregivers to Manage Medications

Hospitals provide individual guidance in varying ways to ensure family caregivers can understand, afford, reconcile, organize, and administer medications in forms such as pills, eye drops, suppositories, patches, ointments, inhalers, and injections.

Staff pharmacists, pharmacy technicians, and nurses educate family caregivers about medication management, how to know if a medication is working as expected, adverse drug events and interactions, how to mitigate side effects (including those that can mimic symptoms of a condition), what to look for, what to call about, and who to call. They probe for vital information to make the medication reconciliation process as accurate and complete as possible. They address barriers related to adherence and transportation to purchase medications. They also offer opportunities to ask questions about insurance and less expensive alternatives, dosing, directions, dietary restrictions, and alcohol use. Often they can coordinate with the family caregiver's local retail pharmacist or mail-order pharmacy to ensure availability, affordability, and delivery.

Highlighted strategies to provide this information, gathered during our ongoing national CARE Act implementation scan, appear below. Hospital leaders use one or a combination of these strategies, some of which are a direct result of the CARE Act. Some supports were already in place and many are enhanced to achieve consistency across an organization.

1 Providing medications in the hospital or prescriptions before discharge

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

Some health care systems have “meds to beds” programs. Some hospitals focus on high-risk patients at the start of the program.

- Several health care systems have programs that deliver medications from an internal or retail pharmacy to the bedside or home before the day of discharge and provide access to a pharmacist

for questions. They provide a few days' supply to a full 30-day supply. Some hospital pharmacies are open 24/7.

- Some hospitals provide prescriptions before discharge so family caregivers can pick up medications at a retail pharmacy. At some hospitals, pharmacists coordinate directly with the family caregiver's local retail pharmacist.
- At one hospital, the family caregiver picks up medications from the hospital pharmacy as part of the discharge process. Intravenous medications are delivered either to the patient room or home, depending on the equipment required to administer them.

2 Conducting medication reconciliations during multiple transitions

Hospitals have historically conducted medication reconciliation at discharge. The process entails comparing medications taken before the hospital stay with those to be taken at home after discharge—to account for differences, duplications, and gaps. Many hospitals now conduct the medication reconciliation process at one or more additional junctures, such as before, during, or shortly after admission and within days of discharge by phone.

Many hospitals conduct a medication reconciliation upon admission. This helps clinicians determine the effectiveness and safety of the home medication regimen and address during the hospital stay any omissions or lack of adherence.

In the emergency department of one hospital, pharmacy technicians ask patients, “Who fills the medicine box at home?” That helps the techs identify and educate family caregivers. They check the accuracy of the medication box and call the patient's retail pharmacy to confirm the medications the patient has been taking.

3 Dedicating pharmacists to meet with patients and family caregivers

Some hospitals hire staff pharmacists specifically to conduct admission and discharge medication

reconciliations and encourage family caregivers to participate in the discussion in the hospital room. In some pharmacy programs, this practice is part of residency training.

In a hospital where admissions come primarily from the emergency department, pharmacy technicians conduct the medication reconciliation process while individuals and family caregivers wait to be seen in the emergency department. Pharmacists consult with high-risk individuals. There are three significant benefits of this timing:

1. A family caregiver is typically present in the emergency department, so the timing takes advantage of that person's presence and insights.
2. Clinicians get an accurate medication list that informs the medical history and physical examination they will conduct—which is especially helpful during clinical evaluations of high-risk or frail older adults and those taking multiple medications.
3. Having this up-to-date information in the patient record speeds the discharge process.

4 **Establishing a robust discharge suite staffed by nurses**

At some health care systems, medication management support is part of a systemwide transitions of care program that includes separate transition suites. These discharge suites include dedicated nurses who give family caregivers the unhurried focused attention they need to fully understand and prepare for their postdischarge responsibilities. These suites are an improvement to 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 learn about the medications they will be managing, get help finding them at affordable prices, and practice with supervision the medical/nursing tasks they will perform at home.

For additional details about supporting family caregivers during care transitions, see [Transitions in Care and Postdischarge Support Practices to Improve Patient and Family Engagement: 16 Ways to Prepare Family Caregivers for Their Postdischarge Responsibilities](#) in this publication series.

5 **Ensuring family caregiver understanding by using the teach-back method—throughout the hospital stay**

Health care systems recognize the effectiveness of the teach-back method of instruction to ensure those receiving care and family caregivers understand discharge instructions and the care plan they will implement at home.

Hospital staff use this instructional method to allow family caregivers to hear instructions, repeat back in their own words what they've learned, see demonstrations of administering injectable and other medications, practice caregiving tasks with supervision, receive feedback, and ask questions.

Staff use teach-back during multiple learning opportunities throughout the hospital stay to reinforce the enormous amount of information family caregivers must digest and master.

6 **Making postdischarge follow-up phone calls to the home**

Staff pharmacists or nurses at many hospitals make one or more follow-up calls to the home, 1 to 3 days after discharge. One hospital also makes 90-day follow-up calls. Some health care systems provide a nurse hotline staffed through a dedicated call center; in other systems, specially trained unit nurses make calls. One health care system organizes its calls through a centralized case management structure.

One hospital calls every patient's home after discharge and tracks issues as part of its CARE Act implementation. The staff note anecdotally that the most common issues relate to medications and arranging support services at home and that family caregivers seem more comfortable asking questions by phone after discharge than in person in the hospital.

7 **Setting up focused follow-up appointments with primary care providers**

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 the appointment is to follow up on details of the hospital stay rather than 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 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 subsequently roll out successful ACO programs to all patients.

8 Adding to the EHR a list of medications older adults should potentially avoid

Some health care systems build a tool into the EHR to provide decision support and alerts that help prescribers avoid potentially inappropriate medications for older adults. They include sample language in the EHR to help prescribers use consistent language to facilitate understanding when talking with care recipients and family caregivers.

For additional details about EHR enhancements that support family caregivers, 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.

9 Sharing educational materials about frequently used medications

At one hospital, a surgery unit distributes a booklet staff developed on frequently used postoperative medications.

For additional details about educational materials for family caregivers, see [Learning Resources and Practices to Improve Patient and Family Engagement: 12 Ways to Facilitate Family Caregiver Education in Hospitals](#) in this publication series.

10 Assisting with affordability

With the goal of ensuring that all who leave the hospital with prescriptions are able to fill them, nurses at one health care system call prescribers to arrange for a less costly substitute, or they obtain coupons for family caregivers to use at a retail pharmacy. At some hospitals, social workers

collaborate with family caregivers to ensure medications are affordable. At hospitals with transition suites, discharge nurses work with family caregivers to find low-cost medications.

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 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.¹⁸

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 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 of Preparing Family Caregivers to Manage Medications

Hospital leaders identify obstacles to preparing family caregivers to understand, manage, and administer medications 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: There are not enough resources to provide the ideal level of support to every family caregiver.



Resolutions: Hospitals scale approaches over time. Some hospitals tie interventions to a specific need. An example is prioritizing postdischarge calls to those with high-risk conditions who are identified as having low medication adherence and literacy. Other follow-up call strategies appear earlier in this paper.



Challenge: Family caregivers in the hospital often cannot process information about medication regimes because they are caught

off guard about the level of responsibility they face or are too anxious to digest information.



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



Challenge: Discharge delays occur when family caregivers aren't available for medication reconciliation and instruction.



Resolution: Hospitals provide instruction throughout the hospital stay at times convenient for staff and family caregivers. Hospital staff anecdotally report significant decreases in medication discrepancies by having a standard process.

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

Medication Management Form for Individuals

AARP provides a template called *My Personal Medication Form* in English and Spanish. It is available at https://www.aarp.org/health/drugs-supplements/info-2007/my_personal_medication_record.html.

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](#)SM, a collaborative of AARP, and funded by The John A. Hartford Foundation.¹⁹

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.^{20, 21}

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.

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)
- [Communication Practices to Improve Patient and Family Engagement: 10 Ways to Identify and Engage Family Caregivers in Hospitals](#) (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)

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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

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