

# LEARNING RESOURCES AND PRACTICES TO IMPROVE PATIENT AND FAMILY ENGAGEMENT:

## 12 WAYS TO FACILITATE FAMILY CAREGIVER EDUCATION IN HOSPITALS

### ABOUT THE SERIES

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

The Caregiver Advise, Record, Enable (CARE) Act is now law in more than 40 states and territories. Policy makers recognize that family caregivers need support to perform the medical/nursing tasks they face at home after a family member or friend is discharged from the hospital.

The landmark 2012 AARP and United Hospital Fund report *Home Alone: Family Caregivers Providing Complex Chronic Care*, funded by The John A. Hartford Foundation, drove rapid adoption of the CARE Act. The report also inspired the creation of the Home Alone Alliance<sup>SM</sup>, a partnership of public, private, and nonprofit US organizations coming together to change the way health care organizations and professionals interact with family caregivers.

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

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

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

### Overview

More than 20 million family caregivers perform increasingly complex medical/nursing tasks at home after a family member or friend is discharged from the hospital.<sup>1</sup> Health care systems recognize that guiding and instructing family caregivers throughout a hospital stay and beyond helps better prepare them to provide that complex care. This support helps family caregivers manage the care recipient's ongoing comfort and quality of life and avert complications that can lead to costly emergency department visits and readmissions.

#### **A Holistic Approach:**

#### **Educating Family Caregivers and Training Staff**

**Health systems are responding to this shift by providing learning resources to family caregivers to help them do the following:**

- **Understand their role in the patient's care.**
- **Prepare to perform the medical/nursing tasks they face after hospital discharge.**
- **Reinforce learning during the hospital stay and at home by accessing culturally appropriate resources.**

Hospitals also teach staff, such as nurses, pharmacists, occupational and physical therapists, social workers, case managers, discharge planners, respiratory therapists, nurse practitioners, physician assistants, and physicians, how to include family caregivers as integral members of the care team throughout the hospital stay.

Clinicians learn to anticipate what family caregivers need to know, encourage their input in decision making, and prepare them for the care they will provide at home. This approach also helps improve care coordination and prevent discharge delays.

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

#### **➔ Learning resources for family caregivers**

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

When family caregivers are asked what would make it easier for them to perform medical/nursing tasks at home after discharge, they report they want more and/or better instruction.<sup>2</sup> More preparation would help them with the challenges of tasks such as caring for wounds, managing intense pain, and administering pills, suppositories, and injections.

Their preferred instructional formats include additional exposure to the content during the hospital stay, practice with supervision, written instructions, visual instruction, videos, consistency in instructions, and a phone number to call with questions.<sup>3</sup>

## Lost In Translation: A Vignette

The example below illustrates gaps in family caregiver knowledge, subsequent consequences, and opportunities for system change. The promising practices shared in this paper can help prevent those gaps.



**Example:** Anna is hospitalized after a fall and has surgery to repair her fractured shoulder. Her son, David, and his wife, Sofia, come to visit after work each day and focus on Anna's comfort and concerns. They don't realize the complexity of care they face after discharge, so they aren't asking the staff questions about how to take care of Anna's shoulder wound at home.

David is unprepared when the discharge planner calls him at work to tell him his mother will be ready to go home in a few hours. David and Sofia hurry to the hospital. The nurse talks to them about Anna's care and gives them a large packet of written instructions. After they rush to get the supplies they need and get home, they realize they can't remember all the details of their instructions. They speak another language at home, and they have trouble understanding complex written instructions in English. The translated instructions they do receive are not translated correctly and confuse them even more. They wish someone had shown them how to care for the wound while Anna was in the hospital. Maybe then they would have known what questions to ask.

In the middle of the night, David struggles to help Anna get out of bed to use the bathroom and notices blood on her shoulder dressing. She is in pain and shaking,

and she seems weak. He worries that her wound is bleeding too much. David and Sophia panic and call an ambulance to take Anna to the emergency department instead of calling the phone number the hospital provided.



**Repercussions:** Anna was readmitted. David and Sofia experienced a great deal of disruption from an additional hospital stay and worry because they didn't know how to help Anna, who was distraught.



**Opportunity:** It would be more cost-effective for the hospital to identify family caregivers like David and Sofia and engage them when they are visiting the person receiving care—providing hands-on instruction, guidance, and reinforcement throughout the hospital stay—than to incur a readmission penalty. Discharge instructions could reflect the cultural norms and terms familiar to families living in the hospital's service area. The instructions could address pain management, mobility, wound care, and other important details.

David and Sofia would be prepared to care for Anna, look for warning signs of complications, feel empowered to take action, and respond appropriately before a problem develops.

## 12 Highlighted Practices

### Ways to Optimize One-on-One Interactions with Family Caregivers for Instruction and Support

Health care systems use new approaches to prepare family caregivers to provide care at home after hospital discharge. Highlighted practices from our ongoing national CARE Act implementation scan include the activities listed below.

#### 1 Understanding family caregiver willingness

The most important gauge of preparation for family caregiving may be the person's expressed willingness to receive instruction and participate in postdischarge care. Hospital staff bear in mind that some visiting family members or friends may not be willing or physically able to be involved with care at home, and that others who are not present may be more than willing.

#### 2 Conducting a family caregiver needs assessment to determine readiness and appropriate resources

Staff recognize that an individual has different needs and pressing concerns over the course of the caregiving journey. The beginning of caregiving often entails being in a state of shock after a sudden health crisis. Family caregivers managing such a crisis have

little awareness of the caregiving role and health care culture, and they are unable to fully process new information. In contrast, seasoned caregivers might feel confident about managing their caring responsibilities but could be experiencing physical and mental health problems of their own as a result of years of stressful hands-on caregiving.

Before hospital staff provide resources, they assess primary family caregivers to understand their willingness, readiness, concerns, and priorities, and then determine which resources will be most beneficial to them as they provide care at home.

The assessment determines family caregivers' ability and readiness from emotional, physical, and practical perspectives. It also evaluates literacy and health literacy levels, both of which inform how staff engage the family caregiver and provide instruction and support.

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### 3 Screening to identify barriers

The assessment of family caregiver readiness also screens for barriers to family caregiving related to social determinants of health (e.g., living arrangements, employment, food stability); cultural and language differences; level of general and health literacy; and visual, hearing, and other impairments. The result indicates which resources are appropriate and where gaps in resource availability exist.

Promising practices in hospitals help ensure that information is available and understandable for all literacy and health literacy levels. To facilitate family caregiver education, hospitals account for diverse family caregiving situations and the cultural appropriateness of learning resources. They use multiple channels that span the entire hospital stay and beyond to ensure they reach as many family caregivers as possible.

Because different learning styles and abilities can influence the effectiveness of teaching materials, hospitals provide information in various formats. They consider situations in which family caregivers with low incomes might have difficulty accessing online videos or those with low literacy might struggle to read instructions.

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### 4 Engaging in one-on-one instruction with the family caregiver

- Nurses and staff in other roles use the teach-back method during routine bedside care.

- In this educational approach, as staff provide care, they explain to family caregivers what they are doing and why they are doing it in that particular way. They make sure the content is presented in a way that the family caregiver can understand easily.
  - Staff members offer family caregivers opportunities to restate the same information in their own words, to be certain the family caregivers understand the information and feel confident in performing the task at home after discharge.
  - Staff offer opportunities for family caregivers to perform tasks and receive feedback and reinforcement as they practice.
- Individualized attention enables hospital staff to provide appropriate written information to reinforce the live instruction.
- Nurses and other staff increase the effectiveness of one-to-one instruction by doing the following:
  - Proactively arranging bedside appointments, at a time that takes into account the family caregiver's schedule, to create teaching opportunities
  - Providing medical/nursing supplies and teaching family caregivers how to use them
  - Requesting that prescribers order a home health visit to take place after discharge to reinforce teaching, especially when there is a high level of family caregiver anxiety, strain, and worry
- When complex round-the-clock care will be required after discharge, such as following transplant surgery, some hospitals encourage the primary family caregiver to stay overnight in the hospital room and assume responsibility of care for 24 hours with nurse supervision and support.

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### 5 Providing learning opportunities in group settings

- Some hospitals invite family caregivers to attend and participate in rounds when the care team meets to discuss the patient. Family caregivers have the opportunity to receive detailed instruction and valuable reinforcement. Scheduling rounds at a regular time enables family caregivers to plan ahead to attend.
- Health systems offer in-person or web-based support groups and free educational programs as opportunities for family caregivers to learn in nonclinical settings and also to learn from one another.

## Education via System Delivery

### 6 Gathering patient and family caregiver input

Health care system leaders recognize the value of feedback from patient and family advisory councils (PFACs) and make changes to their materials accordingly to help staff include and educate family caregivers. PFAC feedback about relevance of content, what may be missing, and whether the content is useful and delivered appropriately informs resource development.

### 7 Conducting care coordination across the service area

Some regional health communities work across hospital and postdischarge settings to coordinate care and help staff support patients and family caregivers throughout an individual's lifespan.

### 8 Recording support information in the EHR

Hospital staff document family caregiver education in the EHR and provide printed care notes, folders, diagrams, pictures, and verbal instructions to family caregivers. The documentation allows all clinicians involved to prevent duplicating family caregiver education but reinforce instruction as needed.

## Resources Available before, during, and after the Hospital Stay

### 9 Providing videos

- Some hospitals offer videos that are specific to scheduled procedures to prepare family caregivers beforehand.
- Health systems track the number of times viewers access videos before, during, and after the hospital stay to help them understand the educational value of the videos and the extent to which caregivers use those resources.

### 10 Using existing delivery channels to normalize the role of family caregivers

With or without a formal family caregiver strategy or program in place, hospital systems incorporate family caregiver-focused information (or links to it) into existing delivery mechanisms, processes, formats, programs, and touchpoints, such as discharge instructions, the patient portal, and billing statements.

Some health systems also incorporate family caregiver-focused information into existing printed

materials, digital signage, and web-based platforms. Hospitals share the following promising practices:

- Provide plain-language placards listing local and/or national family caregiver resources in family waiting areas and/or patient rooms, on-demand videos via the patient portal, online videos accessible before and after discharge, and DVDs.
- Make these resources available in the languages (and, when possible, cultural appropriateness) of the patient population.
- Provide user-friendly technology, such as a tablet, to enable access to learning resources. Interactive care technologies can also enable educational materials to be provided on mobile devices.
- Create versions of information for those who are hard of hearing and those who use video and audio devices as well as in-person translators.
- Develop content for family caregivers that addresses the following:
  - The importance of the family caregiver's role as part of the care team
  - Topics such as specific conditions and medication management and side effects
  - A checklist of tasks to prepare for an anticipated hospital stay

## Building System-Wide Buy-In

### 11 Creating materials that address frequently asked questions and sharing them throughout the health system

- One health system provides a curriculum on common caregiving tasks.
- One system develops "What to Look For" printed materials for patients and families.
- The cardiac surgery unit at one hospital distributes a booklet it developed on frequently used postoperative medications.
- Departments of some specialties teach families about upcoming surgery and recovery prior to admission.

### 12 Conducting pilot programs

After one hospital piloted a teach-back program in a single unit, and demonstrated value, other units asked for the program. Eventually the program was implemented throughout the entire hospital.

## Quantifying the Benefits

### Benefits of Learning Resources for Family Caregivers

#### For 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**—Primary family caregivers who receive complete instruction and preparation can relay information to other family members and friends, saving hospital staff the time and energy spent repeating the same information to multiple individuals.
- **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. They 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 instructing 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 Family Caregivers

- **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.<sup>4</sup>

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 Family Caregiver Education

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



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



**Resolutions:**

- Allow the patient to record bedside instruction to share with the family caregiver.
- Consider performing procedures at a time of day when the family caregiver can be present.
- Make specific appointments with the family caregiver to receive instruction.
- Provide instruction during all shifts.



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



**Resolution:** Understand the needs of the populations each hospital serves and develop or obtain culturally appropriate materials. For example, one hospital uses tablets to videoconference with live translators when the appropriate in-person translator is not available.



**Challenge:** Documentation of family caregiver education is 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 patients 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](mailto:homealonealliance@aarp.org).

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

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

#### 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](#)<sup>SM</sup>, a collaborative of AARP, and funded by The John A. Hartford Foundation.<sup>5</sup>

The [Supporting Family Caregivers Providing Complex Care](#) series of publications is based in part on insights in [Home Alone Revisited](#) and [The CARE Act Implementation: Progress and Promise](#), a 2019 AARP Public Policy Institute Spotlight report.<sup>6,7</sup>

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

The [National League for Nursing \(NLN\)](#) offers simulation modules 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

- [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)

Publications in the *Supporting Family Caregivers Providing Complex Care* series are available at [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone). For more information about the CARE Act, visit the AARP Public Policy Institute website or <https://states.aarp.org/tag/the-care-act>. To learn more about the Home Alone Alliance, visit [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone).

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

<sup>2-6</sup> Ibid.

<sup>7</sup> Susan C. Reinhard et al., *The CARE Act Implementation: Progress and Promise* (Washington, DC: AARP Public Policy Institute, March 2019), <https://www.aarp.org/ppi/info-2017/from-home-alone-to-the-care-act.html>.

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