

# Implementing New York State's CARE Act A Toolkit for Hospital Staff



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The strategies, recommendations, and tools included in this publication are intended to provide a basic framework for implementing New York State's CARE Act that can be customized to meet the needs of individual hospitals regardless of size, academic teaching status, staffing model, patient population, or available resources. United Hospital Fund makes no representations or warranties of any kind regarding the toolkit, including, without limitation, as to the accuracy of the information provided. The information provided is not medical or legal advice and should not be relied upon as such, nor should the information be used as a substitute for clinical or legal judgment. UHF does not assume liability for any damage or injury from the use or misuse of any information provided herein.



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# Foreword

For more than 20 years United Hospital Fund has been conducting research and documenting the work provided by family caregivers. Through our Next Step in Care website, we provide valuable information and support for caregivers as they assume increasingly complex responsibilities, including medical and nursing tasks, and navigate an evolving health care system.

In this new environment, care is moving steadily from hospital to community, specifically to home—and preparing and supporting those non-professionals who provide or coordinate care in that setting is critical. While our earliest efforts brought national attention to the demands on caregivers and the impact on their lives, we have increasingly focused on improving partnerships between family caregivers and health care professionals. The dual goal: easing the burden on family and friends, and ensuring better transitions from hospital or nursing home to home, to improve ongoing patient care.

New York State’s CARE (Caregiver Advise, Record, and Enable) Act, the subject of this toolkit, recognizes the need to identify family caregivers early in a hospital stay, include them in discharge planning, and provide instruction for post-acute care at home. This legislation, developed by AARP, has been enacted in more than 30 states. It was inspired by the joint AARP/UHF study, *Home Alone: Family Caregivers Providing Complex Care at Home*, which revealed the extent of caregiver responsibilities for medical/nursing tasks.

The toolkit is a continuation of our partnership-building work with health care providers, including the three-year Transitions in Care–Quality Improvement Collaborative (TC-QuIC). It guides hospitals through the creation of a formal process for meeting the CARE Act’s requirements, and federal and state regulations as well. It also addresses an important addition to the four steps outlined in the Act: follow up to help caregivers meet the challenges of carrying out the hospital’s post-discharge plan. A companion guide, available on the Next Step in Care website in both short and longer versions, explains the CARE Act to patients and caregivers. Both the toolkit and the patient/caregiver guides were produced with the support of The Fan Fox and Leslie R. Samuels Foundation, Inc.

We see this as a continuation of our long history of partnering with New York’s hospitals to address issues ranging from quality of care to innovative service delivery. Our goal remains, as always, to build a more effective health care system for every New Yorker.

JAMES R. TALLON, JR.  
President  
United Hospital Fund

## **Acknowledgments**

Throughout the process of developing this toolkit and the related Next Step in Care guides for patients and family caregivers, United Hospital Fund has consulted with many different individuals at several health care and community-based organizations. We gratefully acknowledge the reviews and suggestions of the following:

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Medicare Rights Center  
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Northwell Health  
SAGE (Services & Advocacy for GLBT Elders)  
Saratoga Hospital  
Sunnyside Community Services  
Upstate University Hospital

We are also extremely grateful for the generous support of The Fan Fox and Leslie R. Samuels Foundation, Inc.

# Introduction

Improving transitions of patients from hospital to home is a national priority for health care providers, administrators, government regulators, and payers, as well as those most directly affected—patients and families. While the immediate goals may vary—reducing avoidable readmissions, improving patients’ experiences, or preventing medication errors, for example—the basic aim of providing a continuum of high-quality care is paramount for everyone. During the past several years many voluntary initiatives have led to improvements in hospital processes around discharge planning, but more remains to be done. It is especially important to engage family caregivers effectively in the discharge planning process and prepare them for post-discharge care.

## **Improving transitions through the CARE Act**

New York State’s Caregiver Advise, Record, and Enable (CARE) Act was developed by AARP and has been enacted in slightly different versions in more than 30 states. The law turns some recent voluntary initiatives into legal requirements. It also adds a special focus—*attention to identifying and preparing a caregiver chosen by the patient to provide post-acute care at home*. Many of the activities required by the CARE Act, which went into force in April 2016, are already in place in New York hospitals; but even so, the caregiver’s role in the discharge process is not always clearly defined. (See Appendix A for the text of the CARE Act and Appendix B for a “Dear Administrator” letter from the New York State Department of Health.)

The CARE Act’s requirements add to but do not replace existing [New York State](#) and [federal](#) laws and regulations around the need for discharge planning (§482.43) and well-implemented transitions from hospital to home or transfers to rehabilitation facilities. Additional [federal requirements have been proposed](#) by the Centers for Medicare and Medicaid Services (CMS) but as of December 31, 2016, final regulations have not been published or withdrawn. (See Appendix C for a crosswalk outlining the similarities and differences among federal and State rules, including the CARE Act.)

#### **ADDITIONAL READING**

**[“Family Caregivers as Partners in Care Transitions: The Caregiver Advise Record and Enable Act”](#)** by Eric A. Coleman, MD, provides information to hospitalists and other staff about implementing the CARE Act in states that have enacted versions of the law. Especially useful is a table providing links to the main transitional care programs, which have tools that help meet the requirements of the CARE Act.

#### **Development of this toolkit**

To assist hospital staff in implementing the CARE Act effectively, United Hospital Fund (UHF) has prepared this toolkit, which not only addresses what the law requires but also suggests points to consider that are not specifically covered in the law.

*Implementing New York State’s CARE Act: A Toolkit for Hospital Staff* is based on UHF’s Next Step in Care portfolio of web-based tools— [www.nextstepincare.org](http://www.nextstepincare.org) — which in turn grew out of 20 years’ experience working to improve partnerships between family caregivers and health care professionals. It includes information drawn from UHF’s three-year [Transitions in Care–Quality Improvement Collaborative \(TC-QuIC\)](#), as well as material from other transitional care initiatives. The toolkit is based on our best understanding of the law; specific legal questions should be addressed to hospital attorneys or the New York State Department of Health.



**In addition to the toolkit for hospital staff, UHF has prepared *New York State’s CARE Act: A Guide for Patients and Caregivers* and a companion brief guide. Both guides are free and available in English, Spanish, Chinese, and Russian. These guides can be downloaded and distributed to patients and caregivers to supplement staff explanations.**

## How the toolkit is organized

The toolkit is organized around four key requirements of the CARE Act. A fifth section addresses follow up after discharge, which is not mentioned in the CARE Act but is important to close the transition loop. According to the CARE Act, hospitals must:

1. As soon as possible after admission, **offer a patient an opportunity to identify a caregiver** who will be able to help with post-acute care at home; **document the caregiver's name and contact information (or the patient's unwillingness to name a caregiver)** in the EMR;
2. **Obtain written consent to share medical information** with the designated caregiver, or document refusal;
3. Consult with patient and designated caregiver about discharge options and post-acute care needs and **inform caregiver about anticipated discharge date;** and
4. **Provide needed instruction to caregiver** as soon as possible, but no later than 24 hours before discharge.
5. **After discharge, follow up with patients and caregivers to identify problems and answer questions.**

The steps outlined in sections 1 through 3 of the toolkit lead up to the primary purpose of the CARE Act, addressed in section 4: to ensure that caregivers are given instruction and preparation for taking care of patients when they are discharged home. The 2012 AARP Public Policy Institute/UHF study, [Home Alone: Family Caregivers Providing Complex Chronic Care](#), as well as other studies, documented that family caregivers doing medical/nursing tasks were poorly trained, if trained at all.

Appendix D provides a graphic timeline of these critical CARE Act activities, prepared by the Greater New York Hospital Association.

While it is important for all staff to understand hospital policies and procedures, some sections of the toolkit will be more directly relevant to different staff members as they integrate the CARE Act into their regular routines. Each section includes a description of the CARE Act requirement, frequently asked questions, and links to additional resources about that topic. The Appendices contain additional documents related to the overall implementation effort.

## Getting Started: Organizational Planning

Implementation of the CARE Act will be most effective if it is based on an organizational review of current policies and procedures as well as implementation options. Among the questions to be addressed, perhaps by a special task force, are:

- Which departments should be involved in implementing the CARE Act?
- Which department should take the lead?
- How will line staff be trained?
- Who will ask the patient about naming a caregiver?
- Who will ask the patient for written consent to share information?
- Will there be a special consent form or will the caregiver consent be added to the general consent?
- Does the current electronic medical record (EMR) have a field for caregiver contact information?
- What kind of resources will be needed?
- What kinds of instruction will be provided to designated caregivers?
- Who will do the teaching?
- How will the implementation efforts be monitored?
- What kinds of outcomes are most important?
- What kinds of information will be provided to patients and caregivers about the CARE Act?

## 1

## Identify and document the patient's designated caregiver

### Defining “caregiver” in the CARE Act

As soon as possible after admission, the patient must be given at least one opportunity to identify a caregiver—defined in the CARE Act as *“any individual... who provides after-care assistance to a patient living in his or her residence. An identified caregiver shall include, but is not limited to, a relative, partner, friend, or neighbor who has a significant relationship with the patient.”* The caregiver may be a person who is hired and paid privately. Home care aides hired through a licensed or certified home care agency may not be able to perform all the required tasks because their scope of practice is limited by specific regulatory standards.

Asking about a caregiver may seem straightforward, and for many patients and their caregivers it will present no problems. But many patients don't recognize a family member or friend as a “caregiver”; that term, they believe, applies only to professionals such as doctors or nurses. If that happens, an alternate phrasing of the question, such as “who helps you at home?” may work. Some patients may even resist the idea of someone “helping” because it suggests that they are not or will no longer be independent.

*Other questions to ask if the patient has trouble deciding whom to name:*

- Who goes with you to doctor appointments?
- Who would you call in an emergency?
- Who helps with your medications?
- Who lives near you?
- Who knows about your medical history?
- Who is involved with your care now?



**During this process, ask the patient to identify the person most likely to assume responsibility for care after discharge, who may or may not be the person who is the legal health care proxy or has financial power of attorney.**

### Assigning specific staff to interview patient

Generally, nurses and social workers are most likely to have this responsibility. How the question is asked is critical to getting a useful answer. *What is most important is not the job title but the person’s communication and “people” skills.* The patient may be confused, disoriented, or in pain; answering questions about going home may not seem as important as getting immediate attention for symptoms and comfort. A lot of information has to be obtained on admission, but this question should be given special attention.

### Updating the record

Be sure to enter the caregiver’s name, contact information, and roles in care in the electronic medical record (EMR) where all members of the care team can easily see and use this information in coordinating the discharge plan. (See Appendix E for a graphic illustration of the documentation requirements in the CARE Act, prepared by the Greater New York Hospital Association.)

## Frequently Asked Questions

**Q: What should I do when the patient is unable to understand or respond to the question because of illness, trauma, pain, or mild or moderate cognitive impairment?**

**A:** The CARE Act does not say what to do if the patient declines to name a caregiver, other than to record that information. The only situation mentioned in the CARE Act is that of an unconscious patient who is temporarily unable to answer the question but will be able to answer when he or she recovers consciousness.

When a patient is unable to respond for other reasons, the most sensible course to follow is to do whatever you would have done before the CARE Act went into effect. There will probably be a family member or friend who has accompanied the person to the hospital; ask that person if he or she will be providing care after discharge. If the answer is no, who will be doing it? Once the patient’s condition has stabilized, the patient may be able to understand or respond to the question and can confirm that the person you have identified is the right one—or not.

If the patient has cognitive impairment, there are communication techniques that make it more likely that he or she will be able to respond. A quiet environment is helpful, though difficult to achieve in a hospital room. Sitting down and looking directly at the patient also helps. Speaking in a conversational tone, not a demanding one, is a good technique. A useful Next Step in Care provider guide is [\*Reducing the Stress of Hospitalization for Dementia Patients and their Family Caregivers\*](#). Although it does not directly address the CARE Act, it offers suggestions for hospital staff on how to talk to patients with cognitive impairment in ways that are calming and reassuring.

**Q: What if the patient doesn't have or can't remember the caregiver's contact information?**

**A:** If someone accompanied the patient to the hospital, or is at the bedside, ask the patient if that person is the one to be named the caregiver. Or ask the visitor to let someone know when that person is present and can be asked for agreement and contact information. It may take a little detective work.

**PRACTICAL TIPS: COMMUNICATION**

**Here are some tips for minimizing the stress of the inpatient stay and improving communication between patients and hospital staff to make it more likely that the patient will be able to participate in the discharge planning process:**

- **Ask the caregiver how the patient likes to be addressed (first name or Mrs. Jones) and whether he or she likes or dislikes terms like "Dearie" and "Honey."**
- **Watch for grimaces, clenched teeth or fists, kicking, or other nonverbal cues that may be typical ways the patient expresses pain. Caregivers are often alert to these signs.**
- **Remember that the patient's behaviors are attempts to communicate. They may be difficult to interpret but they are the only ways a patient with advanced dementia has to express fear, pain, distress, isolation, and confusion.**

***The patient's inability to identify a caregiver does not release the hospital from its obligations under federal and New York State regulations to establish a viable discharge plan.***

**Q: Sometimes patients have more than one caregiver. Does the CARE Act address that?**

**A:** No, the CARE Act requires identifying only one caregiver. But that doesn't prevent staff from adding other individuals to the list in the EMR, with information about who is responsible for what kinds of tasks. It will be important for staff who provide instruction in medication management, for example, to know which caregiver will take over that task.

**Q: What if the caregiver is hesitant about assuming that role?**

**A:** If the potential caregiver appears to be ambivalent, a few follow-up questions may clarify the source of the discomfort and lead the person to reconsider.

- Does the term “caregiver” bother you because you see yourself only as a wife or daughter?
- Are you worried about having to take time off from work?
- Do you live too far away to be available?
- Do you have a health problem that would prevent you from doing some of the tasks?
- Are you nervous about doing injections or monitoring machinery?
- Are you worried that accepting this role will involve financial obligations—for example, paying for some of the hospital bill? Note: The caregiver has no financial obligations beyond those that are already established, for example, for a spouse or an adult child with disabilities for whom the caregiver has guardianship. Remind the caregiver that agreeing to be a caregiver does not mean that he or she will be paid for the work. Only caregivers provided through agencies and covered by insurance, those who are already being paid, or those who are hired by the patient will be paid.

**Q: What should I do if the identified caregiver refuses?**

**A:** The CARE Act states that the person identified by the patient does not have to accept the responsibility. A direct refusal—because the person lives far away, for another logistical or personal reason, or for no stated reason at all—should be accepted without criticizing or shaming the person. An unwilling caregiver will not be able to do the job well, and the patient's discharge plan is likely to fall apart. The

patient should be asked to identify another person. The CARE Act allows the patient to change the designation at any time in the hospitalization; if the identified caregiver is unwilling or unable to fill that role, it is important to pick another person.

*The CARE Act requires only that the patient be given an opportunity to identify a caregiver; it does not say that staff can only ask once.*

If the patient will be eligible for home health care services, a referral may make the identified caregiver more comfortable that he or she will not have to do the job alone.

*Make it clear that this is not a lifelong commitment; it is an agreement to help the patient get home with a realistic discharge plan and referrals to needed services.*

**Q: What if the patient's spouse or adult child disagrees with the patient's choice of caregiver?**

**A:** The CARE Act gives priority to the patient's choice. However, if another person has information that would suggest that the person is unreliable or has other serious limitations, the person taking the information can review the choice with the patient. In extreme cases, a family meeting or ethics consultation may be helpful.

**Q: Does the CARE Act override New York State laws on health care proxies and surrogate decision making?**

**A:** The CARE Act does not affect the rights of an agent or decision-making authority under the [New York State Health Care Proxy law](#) or [New York State Family Health Care Decisions Act \(FHCDA\)](#). If the patient has named a health care proxy and is unable to speak for himself, the proxy becomes the legal actor. If there is no proxy, the FHCDA sets out a hierarchy of family members or others who can make decisions for an incompetent patient. The top priority goes to a court-appointed guardian, if there is one; next in line are the patient's spouse or domestic partner, adult child, parent, brother or sister, or close friend. The FHCDA defines these relationships.

**Q: Although laws and regulations prohibit discrimination against people on the basis of sexual orientation, sometimes instances of disrespectful staff behavior do occur. What can we do to prevent this from happening when asking about caregivers?**

**A:** The CARE Act does not distinguish among different kinds of families, friends, or others who are important in the patient's life. This is actually helpful when asking patients about caregivers because caregiver is a generic term. The LGBT community has a strong, special history of caregiving. Family caregivers or the person receiving care may be gay, lesbian, bisexual, transgender, or questioning. [SAGE](#) and Next Step in Care co-authored a [guide to LGBT caregiving](#) that provides more information on this topic.

**Q: What if the patient has no one to help at home?**

**A:** People who are truly isolated, homeless, or otherwise unable to name a caregiver should be assisted as they would have been before the CARE Act. To ensure a safe discharge, staff will have to try to find services for which these patients are eligible, including supportive housing, clinic care, care management, transportation, and others.

## Points to Remember

- Ask the patient to identify the person most likely to assume responsibility for care after discharge, who may or may not be the person who is the legal health care proxy or has financial power of attorney.
- Make it clear to the caregiver that this is not a lifelong commitment; it is an agreement to help the patient get home with a realistic discharge plan and referrals to needed services.
- The CARE Act requires only that the patient be given an opportunity to identify a caregiver; it does not say that staff can only ask once.

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## Additional Resources

*Next Step in Care guides for health care providers*

### [Identifying the Family Caregiver: A Guide for Health Care Providers](#)

Identifying the caregiver is a first step in establishing a relationship that can yield better patient care and outcomes. Many family caregivers do not identify themselves as “caregivers.” This guide can be helpful for working with those who struggle with this role.

### [Assessing Family Caregivers](#)

This guide for providers offers information about conducting a family caregiver assessment, including links to assessment tools.

### [Assessing Family Caregivers’ Needs—Provider’s Guide](#)

This is a provider version of the *Next Step in Care* [self-assessment guide for family caregivers](#) (below). It includes three separate sections: Availability and Other Responsibilities, What Training Do You Need to Help Your Family Member?, and What Worries Do You Have?

### [Project RED Tool 7: Understanding and Enhancing the Role of Family Caregivers in the Re-Engineered Discharge](#)

This tool systematically reviews the challenges family caregivers face and the support and training they need from staff in the hospital and beyond. It augments the [Re-Engineered Discharge Toolkit](#), initially produced by Boston Medical Center and the Agency for Healthcare Research and Quality.

*Next Step in Care guides for family caregivers*

### [The First Step in Care: Becoming a Family Caregiver](#)

This guide can help explain to a potential caregiver what that role might mean.

### [What Do You Need as a Family Caregiver?](#)

This self-assessment guide for family caregivers asks caregivers to consider their availability, training needs, and worries.

## 2

## Obtain patient's written consent to share medical information with the caregiver

The CARE Act requires that patients give written consent to permit health care providers to share personal medical information with the designated caregiver. This is a more restrictive standard than required by HIPAA, the federal privacy protection law. HIPAA permits (but does not require) health care providers to share medical information with people who provide, manage, or pay for care, as long as the patient does not object.

HIPAA does not require written consent. When state law offers more protection than federal law, as it does in this case, state law sets the standard. (Since the CARE Act applies only to hospitals, HIPAA is still the standard in other health care settings.) All the HIPAA requirements that pertain to security of data, relationships with business entities, and other provisions are unaffected by the CARE Act.

Patients are understandably concerned about protecting their personal medical information from prying eyes, including employers, marketers, ex-spouses, Internet trolls, and others who might use this information to further their own interests. In an age when even supposedly secure databases are vulnerable, caution about sharing information is prudent. Yet most patients *do* want the people close to them to know about their medical conditions, and to provide comfort and care as they go through illnesses and treatments. Such information is particularly important to family caregivers who may have responsibilities such as managing medications, or coordinating follow up for post-hospitalization doctor visits, lab tests, and other encounters with the medical system. Limiting a patient's information to people that the patient chooses or who are clearly involved in care is respectful and supportive of good medical care.

To comply with the CARE Act, hospitals should ask the patient to sign a consent form and document the consent in the electronic medical record. Hospitals may choose to add the designated caregiver to the list of entities, such as insurance companies, mentioned in the general consent signed by patients on admission, or they may choose to create a specific form for this purpose.

## Frequently Asked Questions

**Q: If the patient cannot sign his or her name, is an X sufficient to indicate consent?**

**A:** Yes, but the person witnessing the X should note that the patient could not sign because of illness, disability, or whatever reason and add his or her name to the form as a witness.

**Q: What if a patient is willing to share information about how to perform care tasks at home, but unwilling to share information on the diagnosis or potential side effects?**

**A:** Sometimes patients are unwilling to share certain kinds of information, not because of privacy concerns but because they don't want to upset family members or "burden" them with this knowledge. A conversation about why the patient is reluctant to share information may clear up some misunderstandings. A caregiver has to know the reason for certain treatments or medications or anything that directly relates to care after discharge. Information about past illnesses, such as sexually transmitted diseases or mental health treatments, need not be discussed unless they are relevant to the current condition. Focusing on the present, not the past or the future, may help allay some concerns.

**Q: What about the opposite situation—one in which the family members ask that the patient not be told about a diagnosis?**

**A:** A patient can choose not to know a diagnosis or other information; that person can still give consent for a caregiver to have the information. If there are specific limits to the information that can be shared, they should be documented.

**Q: What if there are multiple caregivers or family members who want to know what's going on?**

**A:** Anyone who has been designated a caregiver should be named in the written consent form. The CARE Act does not prevent caregivers from sharing information with other family members or friends. The patient's wishes, if known, should be respected.

## Points to Remember

- The CARE Act requires that patients give written consent to have health care providers share information with the designated caregiver. HIPAA permits (but does not require) health care providers to share medical information with people who provide, manage, or pay for care, *as long as the patient does not object*.
- *The patient's inability to consent to sharing medical information with a caregiver does not release the hospital from its obligations under federal and New York State regulations to establish a viable discharge plan.*

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## Additional Resources

Next Step in Care

### [HIPAA—Provider's Guide](#)

This guide outlines HIPAA regulations as they apply to sharing information with patients' family and friends.

U.S. Department of Health and Human Services, Office of Civil Rights

### [Does the HIPAA Privacy Rule permit a doctor to discuss a patient's health status, treatment, or payment arrangements with the patient's family and friends?](#)

The enforcement arm of DHHS provides online guidance.

### [Medical Privacy of Protected Health Information](#)

This helpful factsheet from CMS's Medicare Learning Network series clearly states patients' rights under HIPAA and applies to all health care professionals.

## 3

## Inform the caregiver about the expected discharge date

“Discharge planning begins at admission.” This statement has become a standard way health care providers describe how hospitals determine when a patient can be discharged and to what care setting. Such forward-looking planning is not, however, what many patients and caregivers describe as their experience. It often feels to them as though discharge planning occurs at the last minute, just before discharge.

Sometimes a discharge plan can be created even before the patient is admitted. A person having elective surgery, such as a hip replacement, may know ahead of time that the usual hospital stay is a few days, and that a short stay in a rehabilitation unit is recommended before going home. But even in these situations, plans can change because of complications of surgery, shortage of beds in the preferred rehab facility, or other factors.

When the hospital stay is unplanned, it is more difficult to estimate the length of the stay until the hospital staff have some idea of how complicated the case is and what the treatment will include. Patients may ask, “When can I go home?” as soon as they are in their room, which may be too soon to give an answer. However, it is important that patients and caregivers are not totally surprised or given last-minute notification.

Patients and caregivers should be involved in the decision as soon as the care team starts talking about discharge. If, for example, the care team holds interdisciplinary rounds to discuss all the patients on a unit, and identifies those who may be able to be discharged within a few days, that information should be given to the patient and caregiver. Staff should keep the patient and caregiver informed about changes that may affect the timing of discharge, whether that is to home or to a rehabilitation facility. This information should be updated as the team reviews the patient’s progress, and the patient and caregiver notified.

### **When rehab is needed**

If staff feel that a patient cannot go directly home because of slow recovery or complications of surgery or need for other treatment, they may recommend transfer to a rehab facility for continued medical monitoring, or for physical, speech, or occupational therapy.

Unless the possibility of transfer to a rehab facility has been discussed earlier, as in the case of hip replacement surgery, the patient and caregiver may not understand why this option is recommended and what choices of facilities they may have. They may be understandably upset if a nurse or social worker says, “You need to go to a nursing home” without explaining why the transfer is recommended or that it is for a short stay at a rehabilitation unit, and not a permanent move.

Alternatively, rehab services may be provided at home or in ambulatory settings, and these options should also be explored. Patients who are eligible for home health care services should be offered this option, with an explanation of what services a nurse or physical or occupational therapist will provide and why they are important, as well as whether a home care aide will be provided and for how many hours a day or week.

Following New York State regulations on discharge planning (10 NYCRR § 405.9), the CARE Act specifies that, at a minimum, the discharge plan must include:

- (a) the name and contact information of the caregiver;
- (b) a description of all after-care tasks recommended by the discharging physician, taking into account the capabilities and limitations of the caregiver; and
- (c) contact information for health care, community resources, and long-term services and supports necessary to successfully carry out the patient’s discharge plan.

Patients should receive a written discharge plan with this information and all other instructions.



**Patients and caregivers need some time to think about their choices and to understand what they will mean for the short term. A Next Step in Care family caregiver guide, *Leaving the Hospital and Going Where?*, offers useful advice on this aspect of discharge planning.**

## Frequently Asked Questions

**Q: Sometimes a patient or caregiver won't make a decision quickly and the available bed in a rehab unit is no longer available. Can the discharge be delayed while they make up their minds?**

**A:** The CARE Act states that meeting its requirements cannot be used to delay discharges. It is important to give patients and caregivers information early enough in the hospital stay to allow them to consider their options, ask questions, and talk to others. Checking with the caregiver to make sure the contact information on record is correct and the best way to reach the caregiver if it is not the home number will help ensure that the right person is notified about time of discharge home or transfer to a rehab facility.

**Q: What if the patient or caregiver thinks the patient is not well enough to be discharged?**

**A:** The CARE Act does not address this situation. Hospitals are required to give patients information about filing an appeal. Medicare patients can appeal the discharge by calling Livanta, LLC, the Beneficiary and Family Centered Care Quality Improvement Organization for New York State, at 866-815-5440. The acronym QIO (Quality Improvement Organization) may be used to describe this organization. Patients with other forms of insurance should contact the insurer about the appeal process and also seek the assistance of the hospital social worker or patient advocate.

## Points to Remember

- Alerting patients and caregivers ahead of time and checking contact information will help ensure that the right person is notified about time of discharge.
- When a patient will be discharged to a rehabilitation facility and is given a choice about settings, the patient and caregiver need ample advance notice and enough time to weigh their options before making a decision.
- “Discharge planning begins at admission” is not how most patients and caregivers perceive the hospital discharge experience. It is important that patients and caregivers are not totally surprised or given last-minute notification.
- Hospitals are required to give patients information about filing an appeal.

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## Additional Resources

*Guides for health care providers*

[Medication Management—Provider’s Guide](#) and [Medication Management Form](#)

[Project RED Tool 7: Understanding and Enhancing the Role of Family Caregivers in the Re-Engineered Discharge](#)

[Project BOOST’s Discharge Preparation Education Tool \(DPET\)](#)

This is a tool for patients but can be filled out by family caregivers. It lists medications, diet, and other instructions.

*Next Step in Care guides for family caregivers*

[Going Home: What You Need to Know](#)

A discharge checklist for family caregivers.

[Family Caregiver’s Planner for Care at Home](#)

This tool includes a calendar for keeping track of home care visits, contact information, doctor appointments, prescription refills, and other information.

## 4

## Provide instruction to the caregiver

The primary purpose of the CARE Act is to ensure that caregivers are given instruction and preparation for taking care of patients when they are discharged home.

Requiring that hospitals provide instruction to caregivers, however, does not answer all the questions about what level of instruction is needed, what methods should be used, and who should do the training. The act does specify that, at a minimum, the instruction shall include:

*“a live or recorded demonstration of the tasks performed by a hospital employee authorized to perform the after-care tasks... an opportunity for the caregiver and patient to ask questions about the after-care tasks, and [receive] answers to the questions.”*

The law further specifies that the training shall be given in a culturally competent manner and with language translation as required by New York State and federal law.

The CARE Act recognizes that this is a minimal standard. Ideally, patients and caregivers should be given instruction tailored to their individual needs and capabilities, and there should be many opportunities not only to see a demonstration of the task but also to try it out with supervision. (Some hospital policies may limit the kinds of things nonprofessionals are allowed to do to patients, such as giving injections or medications.)

A hospital setting is not ideal for patients and caregivers to learn a new and perhaps difficult task. It is important that staff set aside enough time to repeat the demonstration if necessary, and to use “teach-back”—the process of asking a patient or caregiver to tell the staff member in their own words what they heard and understood. *The teach-back method is meant to test the teacher’s ability to convey information, not the patient’s or caregiver’s ability to understand.* For more information, refer to the U.S. Agency for Healthcare Research and Quality (AHRQ) curriculum on the [teach-back](#) method.

### **PRACTICAL TIPS: USING TEACH-BACK IS BEST**

**Explain things clearly using plain language and avoid using medical jargon and vague directions.**

- **Make sure your patients know your goal is to check how well you explained the health information—not to test their knowledge.**
- **Encourage your patients to use their own words, rather than copying you or others on your clinical team.**
- **Ask open-ended questions that start with “what” or “how” and avoid questions that result in “yes” or “no” answers.**
- **When appropriate, ask your patients to show you how to do something, such as how to check their blood pressure or use their inhaler.**

Source: Agency for Healthcare Research and Quality

In addition, visual aids—videos, drawings, or pictures—all can be helpful, particularly for patients and caregivers who absorb visual information more readily than written instructions. But written instructions are also important as a resource.

### **PRACTICAL TIPS: ADULT LEARNING**

**Principles of adult learning theory may also be helpful in developing training techniques.**

- **Begin by laying out the learning objectives and the knowledge that the caregiver will attain.**
- **Stimulate recall of prior learning. Information is more likely to be transferred from short- to long-term memory (and therefore remembered) when it is attached to a schema or a bundle of information the learner already knows.**
- **Research has shown that learning proceeds more easily if a large list is divided into chunks of about five to seven items, and if each chunk is mastered before the next chunk is taken on.**
- **Move from very simple to increasingly complex information or tasks.**
- **For novice learners, the procedure should be broken down into its most basic tasks, and each step should have a discrete beginning and end.**
- **Demonstrating the whole procedure, followed by the discrete parts, then followed again with the whole procedure has been shown to be effective.**
- **Throughout the process, use plain language and explain any medical jargon.**

Adapted from *“It All Falls On Me”: Family Caregiver Perspectives on Medication Management, Wound Care, and Video Instruction*

Remember that hospital teaching is the first step and is critically important, but that more steps may be needed too. Caregivers should be given a written summary of the instructions in their preferred language. Hospital instructions may need to be adapted for a home setting, because space and equipment are often different or lacking.

Documenting instruction in the EMR gives post-discharge providers such as home health care agency and rehabilitation unit staff basic knowledge about the level of instruction provided. This information should also include areas in which the caregiver needs more training and reinforcement.

Consistency among providers is critical. Caregivers are understandably confused when instructions from different providers conflict. Finally, videos and written manuals can augment training but do not take the place of an individual teacher who can adapt the techniques to the particular patient, caregiver, and setting.

## Frequently Asked Questions

### **Q: Can caregiver teaching be done in a group setting?**

**A:** Some topics might well be addressed in a group—for example, infection control in the home or basic principles of medication management. Then individual instruction can reinforce the basics and focus on the particular patient’s needs. It may be difficult to get caregivers to leave the patient’s bedside to come to a group training, so the sessions should be short and at convenient times. Caregivers should always be given a written summary of the teaching points at the end of the session and a number to call with any questions.

### **Q: How can I find good videos for caregiver training?**

**A:** AARP Public Policy Institute is developing a series of caregiver training videos, and others will be included in AARP’s Home Alone Alliance, a collaboration of organizations concerned with caregiver education and support. The first videos in this series are available at <http://www.nextstepincare.org/Videos/>. There are lots of videos on other online sites as well, but staff should review them carefully before using them to make sure the information is accurate and that the video shows a scenario that will be seen as realistic by patients and caregivers.

If the hospital has a patient education department, ask them for help but make sure they understand that you are looking for caregiver training. A special team of nurses and social workers might review a range of videos and recommend the best ones to colleagues so that there is some consistency across the hospital. Include the links in the discharge materials so that patients and caregivers can review the videos at home.

**Q: Will I be liable if the caregiver makes a mistake at home and blames my teaching?**

**A:** No, the CARE Act specifically states that hospital staff are not liable for caregivers' errors. That said, it is important to do the best teaching possible to avoid errors.

## Points to Remember

- The primary purpose of the CARE Act is to ensure that caregivers are given instruction and preparation for taking care of patients when they are discharged from the hospital.
- At a minimum, the instruction shall include: *“a live or recorded demonstration of the tasks performed by a hospital employee authorized to perform the after-care tasks... an opportunity for the caregiver and patient to ask questions about the after-care tasks, and [receive] answers to the questions.”*
- The CARE Act specifies that instruction shall be provided in a culturally competent manner.
- A hospital setting is not ideal for patients and caregivers to learn a new and perhaps difficult task.
- Principles of adult learning theory may be helpful in designing and developing caregiver teaching techniques.
- Practicing the “teach-back” method can help ensure instructions are being communicated clearly to patients and caregivers. This method measures the effectiveness of the teaching, not the patient’s or caregiver’s knowledge.
- Ensuring that patients and caregivers understand the care plan and care tasks are important parts of care coordination and the “warm handoff” of a care transition.

## 5

## After discharge, follow up with patients and caregivers to identify problems and answer questions

Even after the most carefully planned and implemented hospital discharge, a major challenge can still arise: what happens when the patient and caregiver get home and there are unexpected complications and unanswered questions? *Patients and caregivers should always be given a phone number to call if they have any questions or problems.*

The CARE Act does not say anything about follow up after discharge, but it is prudent and common hospital policy to make follow-up phone calls. This task may be assigned to an experienced care manager or to a care coordinator new to the job. It is important that the person ask relevant questions about the patient's care and the caregiver's comfort level with the tasks, not generic questions such as "How are you doing?" And if the answers indicate some problems, there should be a plan for following up with the relevant clinicians or social workers.

Care coordination presents an opportunity for follow up, not just on medical appointments and lab tests but also on the patient's quality of life and nonmedical needs for transportation, food, home care services, caregiver training, and more. A "warm handoff" between care settings provides a useful opportunity for communication among providers; it also helps ensure that the patient and caregiver have confidence in the post-discharge care plan and are able to implement it safely and effectively.

## Additional Resources

For more information, see the Next Step in Care [Family Caregiver's Guide to Care Coordination](#) and the [Professional Care Coordinator's Guide to Partnering with Family Caregivers](#).

Also see the Next Step in Care guide on [referring family caregivers to home- and community-based services](#).

## Appendix A. The New York State CARE Act

### ARTICLE 29-CCCC

#### CARE ACT (CAREGIVER ADVISE, RECORD AND ENABLE ACT)

Section 2994-hh. Short title.

2994-ii. Definitions.

2994-jj. Caregiver; opportunity to identify.

2994-kk. Notice to identified caregiver.

2994-ll. Instruction to identified caregiver.

2994-mm. Effect on other rights.

§ 2994-hh. Short title. This article shall be known and may be cited as the “CARE act”.

§ 2994-ii. Definitions. When used in this article, the following words or phrases shall have the following meanings:

1. “Hospital” shall mean any “general hospital” as defined in section twenty-eight hundred one of this chapter.
2. “After-care” shall mean any assistance provided by a caregiver to a patient under this article after the patient’s discharge from a hospital that is related to the patient’s condition at the time of discharge. Such assistance shall include, but is not limited to, assisting with basic activities of daily living (ADLs), instrumental activities of daily living (IADLs), and other tasks as determined to be appropriate by the discharging physician.
3. “Caregiver” shall mean any individual duly identified as a caregiver by a patient under this article who provides after-care assistance to a patient living in his or her residence. An identified caregiver shall include, but is not limited to, a relative, partner, friend or neighbor who has a significant relationship with the patient.
4. “Discharge” shall mean a patient’s exit or release from a hospital to the patient’s residence following an inpatient admission.
5. “Entry” shall mean a patient’s admission into a hospital for the purposes of receiving inpatient care.
6. “Patient” shall mean a patient eighteen years of age or older.
7. “Residence” shall mean a dwelling that the patient considers to be his or her home. A “residence” for the purposes of this article shall not include any rehabilitation facility, hospital, nursing home, assisted living facility, group home or other residential health care facility as defined in section twenty-eight hundred one of this chapter or any inpatient facility regulated by the office of mental health.

s 2994-jj. Caregiver; opportunity to identify. 1. A hospital shall provide each patient or, if applicable, the patient's legal guardian with at least one opportunity to identify at least one caregiver under this article following the patient's entry into a hospital and prior to the patient's discharge or transfer to another facility. The hospital shall inform the patient that the purpose of providing the caregiver's identity is to include that caregiver in discharge planning and sharing of post-discharge care information or instruction.

(a) In the event that the patient is unconscious or otherwise incapacitated upon his or her entry into a hospital, the hospital shall provide such patient or his/her legal guardian with an opportunity to identify a caregiver following the patient's recovery of his or her consciousness or capacity.

(b) In the event that the patient or the patient's legal guardian declines to identify a caregiver under this article, the hospital shall promptly document this in the patient's medical record.

(c) The hospital shall record the patient's identification of a caregiver if given by the patient or legal guardian, the relationship of the identified caregiver to the patient, and the name, telephone number, and address of the patient's identified caregiver in the patient's medical record.

(d) A patient may elect to change his or her identified caregiver at any time, and the hospital must record this change in the patient's medical record.

(e) (i) The hospital shall promptly request the written consent of the patient or the patient's legal guardian to release medical information to the patient's designated caregiver following the hospital's established procedure for releasing personal health information and in compliance with all state and federal laws, including the federal Health Insurance Portability and Accountability Act of 1996 as amended, and related regulations.

(ii) If the patient or the patient's legal guardian declines to consent to release medical information to the patient's designated caregiver, the hospital shall not be required to provide notice to the caregiver under section twenty-nine hundred ninety-four-kk of this article or provide information contained in the patient's discharge plan under section twenty-nine hundred ninety-four-ll of this article.

2. An identification of a caregiver by a patient or a patient's legal guardian under this section does not obligate any individual to perform any after-care tasks for any patient.

3. This section shall not be construed to require a patient or a patient's legal guardian to identify any individual as a caregiver as defined by this article.

§ 2994-kk. Notice to identified caregiver. A hospital shall notify the patient's identified caregiver of the patient's discharge or transfer to another hospital or facility licensed by the department or the office of mental health as soon as the date and time of discharge or transfer can be anticipated prior to the patient's actual discharge or transfer to such facility. In the event the hospital is unable to contact the designated caregiver, the lack of contact shall not interfere with, delay, or otherwise affect the medical care provided to the patient or an appropriate discharge of the patient. The hospital shall promptly document the attempt in the patient's medical record.

§ 2994-ll. Instruction to identified caregiver. 1. As soon as possible and not later than twenty-four hours prior to a patient's discharge from a hospital, the hospital shall consult with the identified caregiver along with the patient regarding the caregiver's capabilities and limitations and issue a discharge plan that describes a patient's after-care needs at his or her residence. In the event the hospital is unable to contact the designated caregiver, the lack of contact shall not interfere with, delay, or otherwise affect the medical care provided to the patient or an appropriate discharge of the patient. The hospital shall promptly document the attempt in the patient's medical record. At minimum, a discharge plan shall include:

- (a) the name and contact information of the caregiver identified under this article;
- (b) a description of all after-care tasks recommended by the discharging physician, taking into account the capabilities and limitations of the caregiver; and
- (c) contact information for health care, community resources, and long-term services and supports necessary to successfully carry out the patient's discharge plan.

2. The hospital issuing the discharge plan must offer caregivers with instruction in all after-care tasks described in the discharge plan.

(a) At minimum, such instruction shall include:

- (i) a live or recorded demonstration of the tasks performed by a hospital employee authorized to perform the after-care task, provided in a culturally competent manner and in accordance with the hospital's requirements to provide language access services under state and federal law;
- (ii) an opportunity for the caregiver and patient to ask questions about the after-care tasks; and
- (iii) answers to the caregiver's and patient's questions provided in a culturally competent manner and in accordance with the hospital's requirements to provide language access services under state and federal law.

(b) Any instructions required under this article shall be documented in the patient's medical record, including, at minimum, the date, time, and contents of the instruction.

3. The department is authorized to promulgate regulations to implement the provisions of this article, including but not limited to, regulations to further define the content and scope of any instruction provided to caregivers under this article.

§ 2994-mm. Effect on other rights. 1. Nothing in this article shall be construed to interfere with the rights of an agent operating under a valid health care directive created under section twenty-nine hundred eighty-two of this chapter.

2. Nothing in this article shall be construed to create a new private right of action not otherwise existing in law against a hospital or any of its directors, trustees, officers, employees or agents, or any contractors with whom a hospital has a contractual relationship.

3. A hospital, any of its directors, trustees, officers, employees or agents, or any contractors with whom a hospital has a contractual relationship shall not be held liable, provided it has complied with this article and acted reasonably and in good faith, for the services rendered or not rendered by the caregiver to the patient at the patient's residence.

## Appendix B. “Dear Administrator” Letter



**Department  
of Health**

**ANDREW M. CUOMO**  
Governor

**HOWARD A. ZUCKER, M.D., J.D.**  
Commissioner

**SALLY DRESLIN, M.S., R.N.**  
Executive Deputy Commissioner

May 11, 2016

DHDTC DAL 16 – 06

Dear Chief Executive Officer:

This letter is to inform you about recently enacted legislation, known as the CARE Act (Caregiver Advise, Record and Enable Act), Public Health Law Article 29-CCCC (attached) and effective April 23<sup>rd</sup> 2016. A general hospital inpatient must be given an opportunity to formally identify a caregiver (such as a relative, partner, friend or neighbor) who would provide after-care assistance. This letter will summarize the hospital's responsibilities to comply with this new law and reinforce existing regulatory requirements for patient designated family/representative participation in the patient's discharge plan.

### **OPPORTUNITY TO IDENTIFY CAREGIVER**

The New York State Department of Health expects hospitals to develop a policy and procedure to implement the requirements of the CARE Act. The CARE Act requires the hospital to provide each patient or legal guardian with at least one opportunity to identify at least one caregiver prior to the patient's discharge or transfer to another facility. A caregiver is an individual who provides after-care assistance to a patient who will be discharged home.

Patients are not required to designate caregivers and caregivers are not obligated to perform after-care tasks for patients. The patient must consent to disclose the patient's health information to the caregiver if the patient wants to designate a caregiver. If the patient does designate a CARE Act caregiver, the hospital must include the name and contact information of the caregiver in the patient's discharge plan.

### **NOTICE TO THE CAREGIVER FOR PATIENTS DISCHARGED**

The hospital must attempt to notify the caregiver of the patient's transfer to another health care facility. The hospital must attempt to contact the caregiver prior to a patient's discharge to his or her residence so that the caregiver can provide after-care assistance in accordance with the hospital's instruction to the caregiver.

### **INSTRUCTION TO THE CAREGIVER**

The hospital as soon as possible prior (and if possible, 24 hours prior) to the patient's discharge must consult with the identified caregiver along with the patient regarding the patient's after-care needs at his or her residence. The hospital must offer caregivers instruction in all after-care tasks, taking into account the capabilities and limitations of the caregiver. Instruction to the caregiver is only required for patients being discharged to their homes, not patients being discharged to other health care facilities.

The following written or verbal instruction to the caregiver must be provided:

1. A demonstration of the after-care tasks. The demonstration may be performed live by a member of the hospital's workforce authorized to perform the after-care task, or it may be a recorded demonstration.
2. After the patient and the caregiver have been given an opportunity to ask questions about the after-care tasks, questions will be answered.

The hospital must document in the medical record that the instructions to the caregiver have been given.

### **RELATION TO DISCHARGE PLAN UNDER 10 NYCRR § 405.9**

The requirements for a comprehensive discharge plan to meet a patient's post-hospital needs are specified in 10 NYCRR § 405.9(f). The CARE Act does not change these existing requirements. Instruction to the CARE Act caregiver would not negate the need for home health care or other services. All patients must be assessed for the need for health care services as part of their discharge plan. This includes, but is not limited to, home health care, long-term home health care, hospice, day care and respite care or residential health facility care.

Under 10 NYCRR § 405.9(f), a hospital must ensure that each patient has a discharge plan which meets the patient's post-hospital needs. A patient in need of post-hospital care must be assessed to determine the patient's post-hospital care needs, and the assessment must include an evaluation of the extent to which the patient's personal support system can provide for identified care needs if the patient is discharged home. Consistent with these existing requirements, the CARE Act specifically requires that, if a patient is being discharged home and the patient chooses to designate a CARE Act caregiver, the discharge plan under 10 NYCRR § 405.9 must include:

1. The name and contact information of the caregiver.
2. A description of the assistance with after-care tasks that the caregiver is recommended to provide.
3. Contact information for health care, community resources and long-term care supports to help the caregiver provide after-care assistance.

Should you have questions about the CARE Act, please contact the Division of Hospitals and Diagnostic & Treatment Centers at (518) 402-1003 or by email at [hospinfo@health.ny.gov](mailto:hospinfo@health.ny.gov).

Sincerely,

A handwritten signature in black ink that reads "Ruth Leslie". The signature is written in a cursive style with a light blue shadow effect behind the text.

Ruth Leslie  
Director  
Division of Hospitals and Diagnostic &  
Treatment Centers

Attachment

## Appendix C. Crosswalk of CARE Act and Federal and New York State Regulations on Discharge Planning

The CARE Act is only one of the regulatory requirements governing hospital discharges in New York State. UHF has prepared a crosswalk of the federal and state regulatory frameworks that should be considered along with the CARE Act. The first section outlines nine key points of comparison. The crosswalk then provides more detail on each of the main areas. The crosswalk covers current Centers for Medicare and Medicaid Services (CMS) regulations,<sup>1</sup> proposed CMS regulations,<sup>2</sup> New York State Department of Health (NYSDOH) regulations,<sup>3</sup> and the CARE Act.<sup>4</sup> As of December 31, 2016, CMS had not issued final discharge planning regulations or withdrawn the proposed regulations. In January 2016, NYSDOH issued a report on “Improving the Discharge Planning Process in New York State,”<sup>5</sup> which was put on hold given the uncertainties about the proposed CMS regulations and implementation of the CARE Act. Whether or not NYSDOH moves forward with this improvement plan, it is a useful guide to problems with the current system and proposed changes.

Acknowledgment: Thanks to Leah Reisman, former UHF intern, for organizing the crosswalk materials, and to Frederic Riccardi and Beth Shyken of the Medicare Rights Center for reviewing a draft.

### Nine Key Points of Regulatory Crosswalk

#### 1. Purpose of rule/regulation

NYSDOH regulations and both the current and proposed CMS regulations concerning discharge planning are part of larger frameworks of regulatory requirements. The CARE Act is stand-alone legislation.

<sup>1</sup> Conditions of participation, Discharge Planning. §482.43. Centers for Medicare and Medicaid Services. (2012). Retrieved from United States Government Publishing Office. <https://www.gpo.gov/fdsys/pkg/CFR-2011-title42-vol5/pdf/CFR-2011-title42-vol5-sec482-43.pdf>

<sup>2</sup> Medicare and Medicaid Programs; Revisions to Requirements for Discharge Planning for Hospitals, Critical Access Hospitals, and Home Health Agencies. 80 Federal Register 68125. (November 3, 2015). To be codified at 42 Code of Federal Regulations parts 482, 484, 485. Retrieved from <https://www.federalregister.gov/documents/2015/11/03/2015-27840/medicare-and-medicaid-programs-revisions-to-requirements-for-discharge-planning-for-hospitals>

<sup>3</sup> Admission/discharge. New York Codes, Rules, and Regulations Section 405.9. New York State Department of Health. New York State. (2013). Retrieved from <https://regs.health.ny.gov/content/section-4059-admissiondischarge>

<sup>4</sup> CARE Act. Public Health Article 29-CCCC. New York State. (2016) Retrieved from New York State Senate: <https://www.nysenate.gov/legislation/laws/PBH/A29-CCCC>; also at New York State Department of Health: [https://www.health.ny.gov/professionals/hospital\\_administrator/letters/2016/docs/2016-05-11\\_dal\\_16-06\\_nys\\_phl\\_article29.pdf](https://www.health.ny.gov/professionals/hospital_administrator/letters/2016/docs/2016-05-11_dal_16-06_nys_phl_article29.pdf)

<sup>5</sup> Improving the Discharge Planning Process in New York State. (2016) New York State Department of Health. Retrieved from [https://health.ny.gov/press/reports/docs/discharge\\_plan\\_brief.pdf](https://health.ny.gov/press/reports/docs/discharge_plan_brief.pdf)

## **2. What facilities are affected**

The proposed CMS discharge planning regulations would apply to an expanded list of facilities, including inpatient rehabilitation facilities and home health agencies. All the other rules apply only to general hospitals.

## **3. How “caregiver” is defined**

Both current and proposed CMS regulations define caregivers as “family members, friends, or neighbors, who provide unpaid assistance to a person with a chronic illness or disabling condition.” NYSDOH regulations refer to “patient and family participation” in the decision-making process but do not define caregivers. If the patient is deemed unable to make decisions, the court must appoint a legal guardian. A list of acceptable surrogates is drawn from the Family Health Care Decisions Act. The CARE Act says a “caregiver” can be (but is not limited to) “relative, partner, friend, or neighbor who has a significant relationship with the patient.”

NOTE: Only the CARE Act specifies how the caregiver is to be identified (by the patient). The other regulations are silent on identification, other than the NYSDOH list of surrogate decision-makers.

## **4. Timing and documentation requirements**

All four sets of rules require written documentation on a “timely basis” and inclusion of various elements of discharge in patients’ medical records. CMS’s proposed regulations specify that documentation of patient goals, preferences, and needs must begin “within 24 hours after admission or registration.” NYSDOH requires that a written discharge notice and discharge plan must be given to patients before leaving the hospital. The CARE Act does not specify timing other than notifying the identified caregiver of impending discharge “as soon as the date and time can be anticipated.”

## **5. Consent and information sharing**

CMS and NYSDOH follow federal HIPAA rules. The CARE Act requires the patient’s written consent to share information with an identified caregiver (not required by HIPAA). The CARE Act states that without the patient’s written consent, a caregiver does not need to be notified of impending discharge.

## **6. Training requirements for patient and/or caregiver**

Current CMS regulations say that patients and family members must be counseled to prepare them for post-hospital care. The proposed CMS regulations are more expansive, specifying that staff must consider the caregiver's availability and capability to perform required care; that the discharge plan must include warning signs and symptoms and what the caregiver should do and who needs to be contacted; and that information about follow-up visits, medication, and other needs must be provided. Neither training nor instruction is specifically mentioned in the New York State discharge regulations. The CARE Act requires that the hospital consult with the patient and the identified caregiver before discharge about the caregiver's capabilities and limitations, and that it issue a discharge plan that describes after-care needs. The hospital must offer instruction in all identified tasks; it can use live or recorded demonstrations. There is no requirement that the caregiver be given the opportunity to perform tasks under supervision.

## **7. Written discharge plan**

All sets of rules require a written discharge plan with various clinical elements. The proposed CMS regulations are the most extensive, and include psychosocial history, communication needs, and readmission risk.

## **8. Referrals to community services**

The proposed CMS regulations require access to non-health-related services and community-based providers as part of the discharge plan. The CARE Act says that the discharge plan should include contact information for community resources and long-term services and supports (generally only Medicaid beneficiaries are eligible for such services and supports).

## **9. Enforcement**

Both current and proposed CMS regulations are part of a larger regulatory framework that includes sanctions, fines, and exclusion from reimbursement for Medicare and Medicaid services; a complex system of audits and appeals already exists. NYSDOH lists potential penalties, including fines and the cancellation of contracts, agreements, or licensing. The CARE Act has no audit requirement and no penalties for noncompliance.

## Details of Federal and State Regulations and CARE Act

### 1. Purpose of rule/regulation

CMS (Federal) Current Discharge Regulations	CMS (Federal) Proposed Discharge Regulations	NYSDOH Discharge Regulations	NYS CARE Act
<ul style="list-style-type: none"> <li>Hospitals must meet standards in order to participate in the Medicare and Medicaid programs.</li> <li>Hospitals must have a formal discharge plan in effect that applies to all patients. The hospital's policies and procedures must be specified in writing. (a) Standard: The hospital must identify at an early stage of hospitalization all patients who are likely to suffer adverse health consequences upon discharge if there is no adequate discharge planning.</li> </ul>	<ul style="list-style-type: none"> <li>To revise the discharge planning requirements in the form of six standards at § 482.43. The most notable revision would be to require that all inpatients and specific categories of inpatients be evaluated for their discharge needs and have a written discharge plan developed. At present, hospitals have some discretion and not every patient receives specific, written instructions.</li> <li>To protect patient health and safety</li> <li>To ensure that quality care is furnished to all patients in Medicare and Medicaid-participating facilities</li> </ul>	<ul style="list-style-type: none"> <li>To ensure continuity of care and the most effective utilization of hospital and community-based health and social services</li> </ul>	<ul style="list-style-type: none"> <li>“AN ACT to amend the public health law, in relation to identification of caregivers”</li> <li>Intended to educate and support the individuals who provide vital care to loved ones</li> <li>Caregivers and hospitals work together in the development of a care plan</li> </ul>

### 2. Facilities regulations apply to

CMS (Federal) Current Discharge Regulations	CMS (Federal) Proposed Discharge Regulations	NYSDOH Discharge Regulations	NYS CARE Act
<ul style="list-style-type: none"> <li>General hospitals</li> </ul>	<ul style="list-style-type: none"> <li>General hospitals</li> <li>Long-term care hospitals</li> <li>Inpatient rehabilitation facilities</li> <li>Critical access hospitals</li> <li>Home health agencies</li> </ul> <p>NOTE: Long-term care hospitals accept patients with complex medical conditions who cannot be discharged home (e.g., Calvary Hospital in the Bronx).</p> <p>Critical access hospitals are rural hospitals with 25 or fewer beds not located near general hospitals.</p>	<ul style="list-style-type: none"> <li>General hospitals</li> </ul>	<ul style="list-style-type: none"> <li>General hospitals</li> </ul>

### 3. How “caregiver” is defined

CMS (Federal) Current Discharge Regulations	CMS (Federal) Proposed Discharge Regulations	NYSDOH Discharge Regulations	NYS CARE Act
<ul style="list-style-type: none"> <li>• Caregivers are defined as family members, friends, or neighbors who provide unpaid assistance to a person with a chronic illness or disabling condition</li> <li>• Assistance may include helping the person with activities of daily living, performing medical tasks, or acting as the person’s legal representative</li> </ul>	<p>Same as current CMS regulations</p>	<ul style="list-style-type: none"> <li>• Discharge planning shall include patient and family participation in the decision-making process regarding post-hospital care and the selection of specific services</li> <li>• Patient representative: a member of the hospital staff who serves as a link between the patient, family, physicians and other hospital staff                             <ul style="list-style-type: none"> <li>○ Available to answer questions about hospital procedures, help with special needs or concerns, help solve problems</li> <li>○ No charge</li> </ul> </li> <li>• If patient is deemed unable to make decisions, court must appoint a legal guardian to determine health care</li> <li>• Health care agent: a person that the patient appoints to make his or her health care decisions if he or she loses the ability to do so</li> <li>• Surrogate list from New York State Family Health Care Decisions Act (listed from highest to lowest priority):                             <ul style="list-style-type: none"> <li>○ Spouse, if not legally separated from the patient, or the domestic partner</li> <li>○ A son or daughter 18 or older</li> <li>○ A parent</li> <li>○ A brother or sister 18 or older</li> <li>○ A close friend</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• “Caregiver” shall mean any individual duly identified as a caregiver by a patient under this article who provides after-care assistance to a patient living in his or her residence”</li> <li>• “An identified caregiver shall include, but is not limited to, a relative, partner, friend or neighbor who has a significant relationship with the patient”</li> <li>• Being an identified caregiver under this act does not obligate the individual to perform any after-care tasks for the patient</li> <li>• A patient arriving at the hospital unconscious or incapacitated will be given the opportunity to identify a caregiver once gaining consciousness or capacity</li> </ul>

#### 4. Timing and documentation requirements

CMS (Federal) Current Discharge Regulations	CMS (Federal) Proposed Discharge Regulations	NYSDOH Discharge Regulations	NYS CARE Act
<ul style="list-style-type: none"> <li>• Hospital personnel must complete a written discharge evaluation on a “timely basis” to allow for adequate time to make arrangements for post-hospital care</li> <li>• Discharge planning evaluation must be included in the patient’s medical record</li> <li>• Hospital must document in the patient’s medical record that a list of home health agencies (HHAs) or skilled nursing facilities (SNFs) that are available to the patient was presented to the patient or to the individual acting on his or her behalf</li> </ul>	<ul style="list-style-type: none"> <li>• Evaluation of patient discharge needs and discharge plan must be documented and completed on a timely basis</li> <li>• Discharge plan must be in clinical record</li> <li>• Within 24 hours after admission or registration, anticipated goals, preferences, and discharge needs for each applicable patient must begin to be identified (specific to critical access hospitals);</li> <li>• Discharge planning process must be complete prior to discharge home or transfer to another facility (specific to critical access hospitals but does not apply to emergency-level transfers for patients requiring a high level of care; p. 68154)</li> </ul>	<ul style="list-style-type: none"> <li>• Hospitals are required to identify promptly patients who may need post-hospital care and planning</li> <li>• Hospitals must provide patients with a written discharge notice and a written discharge plan before they leave the hospital</li> <li>• Hospital must provide patient with a copy of “Your Rights as a Hospital Patient in New York State”</li> </ul>	<ul style="list-style-type: none"> <li>• Hospital must provide each patient or patient’s legal guardian at least one opportunity to identify a caregiver following the patient’s entry into hospital and prior to the patient’s discharge or transfer to another facility</li> <li>• Declining to identify a caregiver under this article must promptly be documented by the hospital in the patient’s medical record</li> <li>• Hospital must document identification of a caregiver, the relationship of the identified caregiver to the patient, and the name, telephone number, and address of the patient’s identified caregiver in the patient’s medical record</li> <li>• “A hospital shall notify the patient’s identified caregiver of the patient’s discharge or transfer to another hospital or facility licensed by the department or the office of mental health as soon as the date and time of discharge or transfer can be anticipated prior to the patient’s actual discharge or transfer to such facility”</li> <li>• Lack of contact with designated caregiver may not interfere with or delay patient care and/or appropriate discharge; attempts at contact must be documented in the patient’s medical record</li> <li>• Any instructions given to the caregiver and patient must be documented in the patient’s medical record with the date, time, and contents of instruction</li> </ul>

### 5. Consent requirements; regulations related to information sharing

CMS (Federal) Current Discharge Regulations	CMS (Federal) Proposed Discharge Regulations	NYSDOH Discharge Regulations	NYS CARE Act
<ul style="list-style-type: none"> <li>• Hospital must provide discharge planning evaluation to at-risk patients AND to other patients upon the patient’s request or the request of a person acting on the patient’s behalf or the physician</li> <li>• Hospital must inform the patient or the patient’s family of their freedom to choose among participating Medicare providers of post-hospital care services; preferences must be honored</li> </ul> <p>According to HIPAA:</p> <ul style="list-style-type: none"> <li>• Patients may instruct providers not to share information about their treatment with their health plan when they pay by cash</li> <li>• Patients are not required to sign consent forms before doctors, hospitals, or ambulances may share information for treatment, payment, and health care operations</li> <li>• As long as the patient does not object, health care professionals covered by HIPAA may provide information to a patient’s family, friends, or anyone else identified by a patient as involved in his or her care</li> <li>• If patient is incapacitated, appropriate information may be shared with patient’s friends or family if it is in the patient’s best interest</li> </ul>	<ul style="list-style-type: none"> <li>• The patient and caregiver(s) must be involved in the development of the discharge plan and informed of the final plan</li> <li>• Critical access hospitals must consider caregiver/support person and community-based care availability and the patient’s or caregiver’s/ support person’s capability to perform required care</li> <li>• The patient and family or interested persons will be counseled to prepare them for post-hospital care in order to better manage health post-discharge</li> <li>• Results of evaluation plan must be discussed with patient or patient representative</li> <li>• Discharge instructions must be provided at the time of discharge to the patient and/or the patient’s caregiver/ support person(s) and the most acute care provider</li> <li>• Critical access hospitals must send a copy of the discharge instructions/ summary within 48 hours of discharge, pending test results within 24 hours of their availability, and all other necessary medical information to practitioners responsible for follow-up care</li> </ul>	<ul style="list-style-type: none"> <li>• Patients may request information, in writing, as may parents or guardians who have authorized their child’s care</li> <li>• Discharge planning will typically involve the patient, family members or care proxy, doctor, and a member of the hospital staff (i.e., discharge planner, nurse, social worker)</li> <li>• Follows same federal HIPAA privacy standards</li> </ul>	<ul style="list-style-type: none"> <li>• Hospital requires written consent of the patient or patient’s legal guardian to release medical information to designated caregiver</li> <li>• If patient or patient’s legal guardian declines consent to release medical information to the designated caregiver, the hospital does not need to inform the caregiver of patient’s discharge plans</li> </ul>

## 6. Training requirements for patient and/or caregiver

CMS (Federal) Current Discharge Regulations	CMS (Federal) Proposed Discharge Regulations	NYSDOH Discharge Regulations	NYS CARE Act
<ul style="list-style-type: none"> <li>• As needed, patient and family members or interested members must be counseled to prepare them for post-hospital care (NOT required)</li> </ul>	<ul style="list-style-type: none"> <li>• Hospital must consider caregiver/support person availability and the patient’s or caregiver’s capability to perform required care as identified in discharge needs</li> <li>• Discharge plan must include instructions to be used by patient or the caregiver/support person(s)</li> <li>• Discharge plan must include instructions on warning signs and symptoms that may indicate need to seek immediate medical attention, accompanied by what the patient or caregiver/support person should do in an emergency situation and who needs to be contacted</li> <li>• Discharge plan must include prescriptions for required medications along with their name, indication, dosage, and significant side/risk effects</li> <li>• Discharge plan must include written instructions pertaining to patient’s follow-up care, appointments, pending and/or planned diagnostic tests, and pertinent contact information</li> <li>• Hospitals should utilize “teach-back” method to ensure patient understanding of transitional care planning and appropriate medication use</li> </ul>		<ul style="list-style-type: none"> <li>• “As soon as possible and not later than twenty-four hours prior to a patient’s discharge from a hospital, the hospital shall consult with the identified caregiver along with the patient regarding the caregiver’s capabilities and limitations and issue a discharge plan that describes a patient’s after-care needs at his or her residence”</li> <li>• “The hospital issuing the discharge plan must offer caregivers... instruction in all after-care tasks described in the discharge plan”</li> <li>• The hospital must provide:               <ul style="list-style-type: none"> <li>- “Live or recorded demonstration of tasks performed by a hospital employee authorized to perform the after-care task in a culturally competent manner and in accordance with the hospital’s requirements to provide language access services under state and federal law” (Sec. 3, Lines 45-49)</li> <li>- “An opportunity for the caregiver and patient to ask questions about the after-care tasks”</li> <li>- “Answers to the caregiver’s and patient’s questions provided in a culturally competent manner and in accordance with the hospital’s requirements to provide language access services under state and federal law”</li> </ul> </li> </ul>

### 7. Need for written discharge plan, and its components

CMS (Federal) Current Discharge Regulations	CMS (Federal) Proposed Discharge Regulations	NYSDOH Discharge Regulations	NYS CARE Act
<ul style="list-style-type: none"> <li>• Hospital discharge policies and procedures must be in writing</li> <li>• Hospital must identify at early stage of hospitalization patients who are likely to suffer adverse health consequences upon discharge if there is no adequate discharge planning</li> <li>• The patient’s physician may also request a discharge plan</li> <li>• A registered nurse, social worker, or other qualified personnel must develop or supervise the development of discharge planning evaluation</li> <li>• Discharge planning evaluation must include:                             <ul style="list-style-type: none"> <li>- Evaluation of the likelihood of a patient needing post-hospital services and the availability of those services</li> <li>- Evaluation of the likelihood of a patient’s capacity for self-care or the possibility of the patient being cared for in the environment from which he or she entered the hospital</li> </ul> </li> </ul> <p style="text-align: right;"><i>(continued)</i></p>	<ul style="list-style-type: none"> <li>• Utilize current federal discharge regulations, with additional clarity</li> <li>• Discharge plans must be written</li> <li>• Hospitals are required to implement a discharge planning process to begin identifying, early in the hospital stay, the anticipated post-discharge goals; this can help reduce delays in the overall discharge process</li> <li>• Providers should be aware of unique and innovative state programs focused on discharge planning</li> <li>• The following should be considered in evaluating a patient’s discharge needs: admitting diagnosis or reason for registration; relevant co-morbidities and past medical and surgical history; anticipated ongoing care needs post-discharge; readmission risk; relevant psychosocial history; communication needs; patient’s access to non-health care services and community-based providers; patient’s goals and treatment preferences</li> <li>• Discharge planning process must ensure that the discharge goals, preferences, and needs of each patient are identified and result in the development of a discharge plan for each patient</li> <li>• Discharge plan must be developed with critical access hospital professionals, health care staff, nursing leadership, and other relevant departments</li> <li>• Discharge plan must be reviewed and approved by governing body or responsible individual</li> </ul> <p style="text-align: right;"><i>(continued)</i></p>	<ul style="list-style-type: none"> <li>• Patient and designated caregiver must receive a discharge notice including :                             <ul style="list-style-type: none"> <li>- Information on patient discharge date and how to appeal if patient disagrees with the notice (Medicare patients receive this notice in the form of an “Important Message from Medicare”)</li> </ul> </li> <li>• Patient and designated caregiver must receive advance notice, in writing, of the discharge plan, including:                             <ul style="list-style-type: none"> <li>- Critical results of laboratory or other diagnostic tests ordered during patient’s stay and identification of any other tests that have not yet been concluded</li> <li>- The date the physician and/or hospital plans to discharge the patient</li> <li>- Arrangements for any health care services needed after leaving the hospital</li> <li>- How to appeal if the patient wishes to remain in the hospital</li> <li>- A statement that "If you are hearing or vision impaired, or if English is not your first language, skilled interpreters must be provided to assist you" (p. 2)</li> </ul> </li> <li>• Necessary services described in this plan must be secured or reasonably available before patient leaves the hospital</li> </ul>	<ul style="list-style-type: none"> <li>• Written discharge plan is required</li> <li>• Necessary components of the discharge plan include:                             <ul style="list-style-type: none"> <li>- The name and contact information of the caregiver identified under this article</li> <li>- Description of all after-care tasks recommended by the discharging physician, taking into account the capabilities and limitations of the caregiver</li> <li>- Contact information for health care, community resources, and long-term services and supports to successfully carry out the patient’s discharge plan</li> </ul> </li> </ul>

7. Need for written discharge plan, and its components *(continued)*

CMS (Federal) Current Discharge Regulations	CMS (Federal) Proposed Discharge Regulations	NYSDOH Discharge Regulations	NYS CARE Act
<ul style="list-style-type: none"> <li>• A registered nurse, social worker, or other qualified personnel must develop or supervise the development of a discharge plan if the discharge planning evaluation indicates a need for a discharge plan</li> <li>• Discharge plan must include a list of HHAs or SNFs available to the patient that are participating in the Medicare program and that serve the geographic area in which the patient resides</li> </ul>	<ul style="list-style-type: none"> <li>• Discharge plans must be developed for all inpatients, outpatients receiving observation services, outpatients undergoing surgery or other same-day procedures with anesthesia or moderate sedation used, emergency department patients, and any other category of outpatients as recommended by the medical staff (applies to critical access hospitals)</li> <li>• A registered nurse, social worker, or other qualified personnel must coordinate the discharge needs evaluation and development of the discharge plan</li> <li>• Discharge planning process must require regular re-evaluation to identify any needed changes to the discharge plan</li> <li>• Practitioner responsible for the patient must be continuously involved in establishing patient goals of care and treatment preferences that inform the discharge plan</li> <li>• Critical access hospitals must establish a post-discharge follow-up process</li> <li>• Patients with limited English proficiency or physical, mental, or cognitive and intellectual disabilities must be provided with meaningful access to the discharge planning process</li> </ul>		

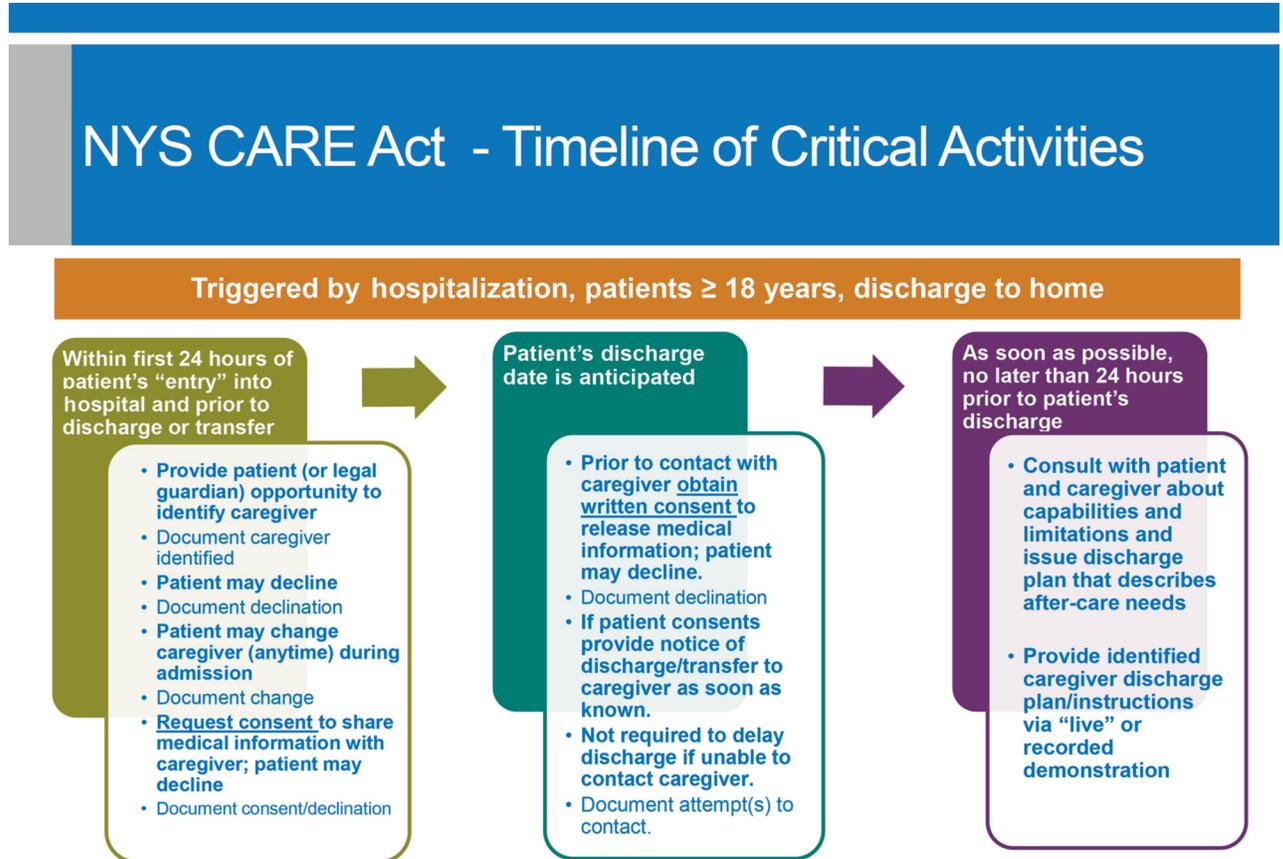
## 8. Referrals to community services

CMS (Federal) Current Discharge Regulations	CMS (Federal) Proposed Discharge Regulations	NYSDOH Discharge Regulations	NYS CARE Act
<ul style="list-style-type: none"> <li>• Hospitals must transfer or refer patients and necessary medical information to appropriate facilities, agencies, or outpatient services for necessary follow-up or ancillary care</li> </ul>	<ul style="list-style-type: none"> <li>• Providers must assist patients and caregivers in selecting a post-acute care provider by using and sharing data relevant to the patient’s goals of care and treatment preferences</li> <li>• Discharge plan must include a list of HHAs or SNFs available to the patient that are participating in the Medicare program and that serve the geographic area in which the patient resides</li> <li>• Hospital to consider the availability of caregivers and community-based care for each patient</li> <li>• Hospital to consider the availability of and access to non-health care resources and social services when applicable</li> <li>• Hospital to assist patients, their families, or their caregivers/ support persons in selecting a PAC provider</li> <li>• Hospitals are encouraged to develop collaborative partnerships with outside providers to help improve care transitions and follow up to better support patient outcomes</li> <li>• Patients discharged home may be given literature to read about medication usage and required therapies; prescriptions for post-hospital medications and supplies; and referrals to post-hospital resources</li> </ul>	<ul style="list-style-type: none"> <li>• Patient may not be discharged until services required in written discharge plan are secured or determined by the hospital to be reasonably available</li> <li>• Patients and family representatives shall be provided with information regarding the range of community services available, for example, home care, skilled nursing facilities, hospice programs, outpatient care or treatment, respite care, community health agencies/programs, mental health agencies/ programs, support service agencies/programs</li> </ul>	<ul style="list-style-type: none"> <li>• Discharge plan must include: “Contact information for health care, community resources and long-term services and supports to successfully carry out the patient’s discharge plan”</li> </ul>

9. Methods to enforce rules and penalties for noncompliance

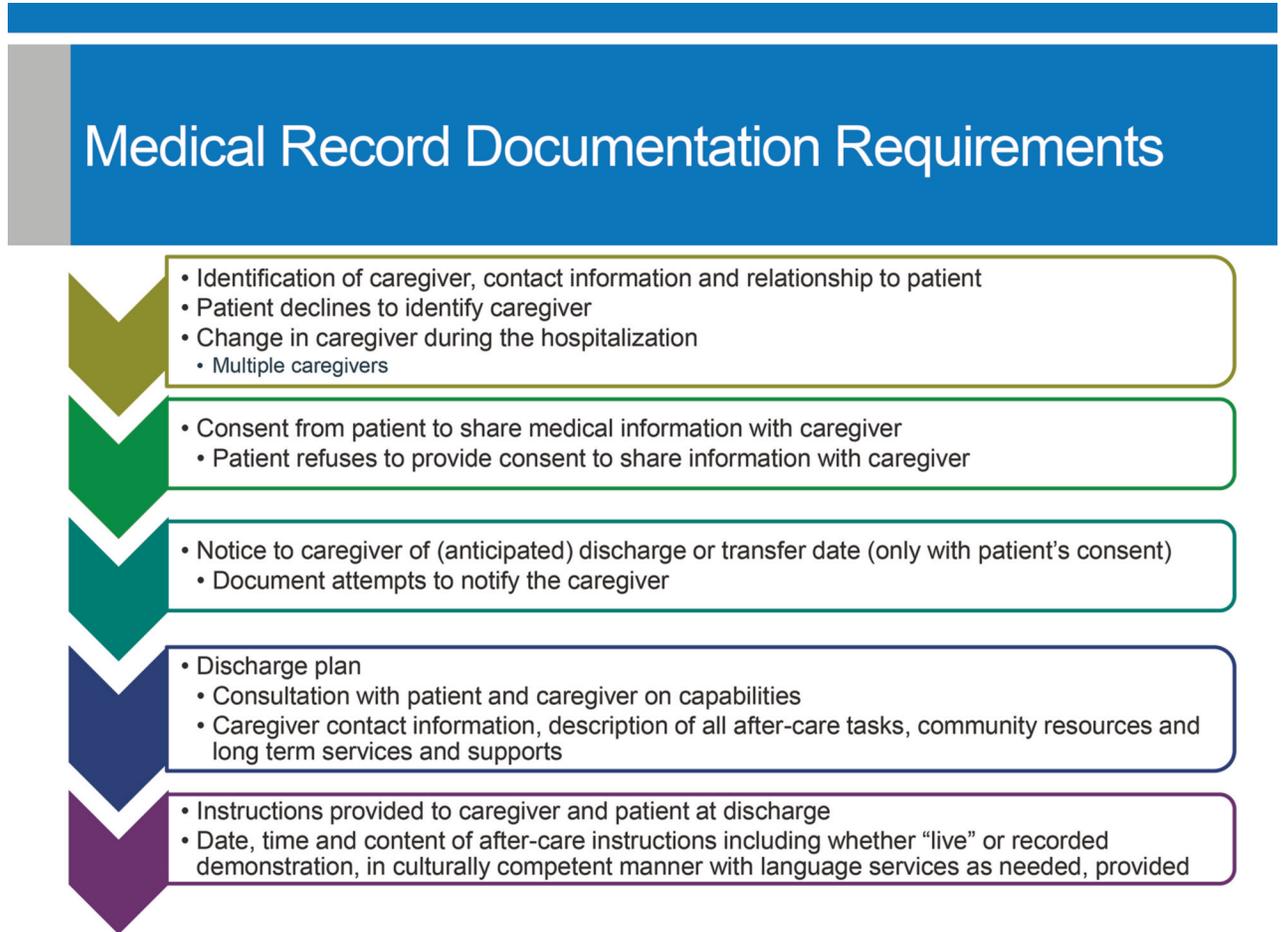
CMS (Federal) Current Discharge Regulations	CMS (Federal) Proposed Discharge Regulations	NYSDOH Discharge Regulations	NYS CARE Act
<ul style="list-style-type: none"> <li>• Hospitals must reassess discharge planning processes on an ongoing basis to ensure that they are responsive to discharge needs</li> <li>• Reassessment must include a review of discharge plans</li> <li>• Discharge planning is part of the conditions of participation in Medicaid/Medicare</li> <li>• Noncompliance with conditions of participation can result in fines. “Failure to comply with a condition of participation can result in sanctions, increased reporting requirements, and eventually, exclusion from participation in the program.”</li> </ul>	<ul style="list-style-type: none"> <li>• Noncompliance with conditions of participation can result in fines. “Failure to comply with a condition of participation can result in sanctions, increased reporting requirements, and eventually, exclusion from participation in the program.”</li> </ul>	<ul style="list-style-type: none"> <li>• “Failure to comply may result in redirection of State funds or State-authorized payments; suspension, modification, limitation or revocation of provider’s license or contracts or other agreements.”</li> </ul>	<ul style="list-style-type: none"> <li>• No explicit mentions of rule enforcement/noncompliance consequences</li> </ul>

## Appendix D. Timeline of Critical CARE Act Activities



The information contained in this slide was developed by the Greater New York Hospital Association for informational purposes only. Please consult with your organization's legal counsel for any questions related to compliance with the law.

## Appendix E. CARE Act Documentation Requirements



The information contained in this slide was developed by the Greater New York Hospital Association for informational purposes only. Please consult with your organization's legal counsel for any questions related to compliance with the law.

## Appendix F. Resources

AARP Public Policy Institute. 2016. *Family Caregiver's Video Guide to Managing Medications*.  
<http://www.aarp.org/ppi/info-2016/family-caregiver-video-guide-to-managing-medications.html>  
 Also available at <http://www.nextstepincare.org/Videos/>

Agency for Healthcare Research and Quality. 2014. The SHARE Approach—Using the Teach-Back Technique: A Reference Guide for Health Care Providers.  
<http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/tools/tool-6/index.html>

Centers for Medicare and Medicaid Services. 2014. Medical Privacy of Protected Health Information Fact Sheet.  
<https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/SE0726FactSheet.pdf>

Centers for Medicare and Medicaid Services. 2012. Conditions of participation, discharge planning. §482.43.  
<https://www.gpo.gov/fdsys/pkg/CFR-2011-title42-vol5/pdf/CFR-2011-title42-vol5-sec482-43.pdf>

Coleman EA. 2016. Family caregivers as partners in care transitions: The caregiver advise record and enable act. *Journal of Hospital Medicine* 11(12): 883-885.  
<http://caretransitions.org/wp-content/uploads/2015/06/JHM-Perspective-CARE-Act-Coleman.pdf>

Federal Register. November 3, 2015. Medicare and Medicaid Programs; Revisions to Requirements for Discharge Planning for Hospitals, Critical Access Hospitals, and Home Health Agencies. *80 Federal Register 68125*. To be codified at 42 Code of Federal Regulations parts 482, 484, 485.  
<https://www.federalregister.gov/documents/2015/11/03/2015-27840/medicare-and-medicare-programs-revisions-to-requirements-for-discharge-planning-for-hospitals>

Levine C, J Rutberg, B Jack, and R Cancino. 2014. *Tool 7: Understanding and Enhancing the Role of Family Caregivers in the Re-Engineered Discharge*.  
[http://www.nextstepincare.org/Provider\\_Home/Project\\_RED](http://www.nextstepincare.org/Provider_Home/Project_RED)

New York State. 2016. Family Health Care Decisions Act. Public Health Article 29-CC.  
<https://www.nysenate.gov/legislation/laws/PBH/A29-CC>

New York State. 2016. Health Care Agents and Proxies. Public Health Article 29-C.  
<https://www.nysenate.gov/legislation/laws/PBH/A29-C>

New York State. 2016. CARE Act. Public Health Article 29-CCCC.  
<https://www.nysenate.gov/legislation/laws/PBH/A29-CCCC>

Also available at

[https://www.health.ny.gov/professionals/hospital\\_administrator/letters/2016/docs/2016-05-11\\_dal\\_16-06\\_nys\\_phl\\_article29.pdf](https://www.health.ny.gov/professionals/hospital_administrator/letters/2016/docs/2016-05-11_dal_16-06_nys_phl_article29.pdf)

New York State Department of Health. 2016. *Improving the Discharge Planning Process in New York State*.

[https://www.health.ny.gov/press/reports/docs/discharge\\_plan\\_brief.pdf](https://www.health.ny.gov/press/reports/docs/discharge_plan_brief.pdf)

New York State Department of Health. 2013. Admission/discharge. New York Codes, Rules, and Regulations Section 405.9.

<https://regs.health.ny.gov/content/section-4059-admissiondischarge>

*Discharge Planning and Education: Project BOOST® Implementation Toolkit*. 2014.

[http://www.hospitalmedicine.org/Web/Quality\\_Innovation/Implementation\\_Toolkits/Project\\_BOOST/Web/Quality\\_Innovation/Implementation\\_Toolkit/Boost/Clinical\\_Tools/Discharge\\_Planning.aspx](http://www.hospitalmedicine.org/Web/Quality_Innovation/Implementation_Toolkits/Project_BOOST/Web/Quality_Innovation/Implementation_Toolkit/Boost/Clinical_Tools/Discharge_Planning.aspx)

Reinhard S and C Levine. 2016. *“It All Falls on Me”: Family Caregiver Perspectives on Medication Management, Wound Care, and Video Instruction*.

<https://www.uhfnyc.org/publications/881158>

Reinhard S, C Levine, and S Samis. 2012. *Home Alone: Family Caregivers Providing Complex Chronic Care*.

<http://www.uhfnyc.org/publications/880853>

SAGE (Service and Advocacy for Gay, Lesbian, Bisexual, and Transgendered Elders) USA. 2012.

<https://www.sageusa.org/>

United Hospital Fund. 2010-2016. Next Step in Care guides for family caregivers and health care providers. *Partial list follows; for additional guides see*

<http://nextstepincare.org/>

### **For Family Caregivers**

- *A Family Caregiver’s Guide to Care Coordination.*  
[http://www.nextstepincare.org/Caregiver\\_Home/Care\\_Coordination/](http://www.nextstepincare.org/Caregiver_Home/Care_Coordination/)
- *Going Home: What You Need to Know.*  
[http://www.nextstepincare.org/Caregiver\\_Home/Going\\_Home/](http://www.nextstepincare.org/Caregiver_Home/Going_Home/)
- *Home Care.* [http://www.nextstepincare.org/Caregiver\\_Home/Home\\_Care/](http://www.nextstepincare.org/Caregiver_Home/Home_Care/)
- *Hospital Discharge Planning: Leaving the Hospital and Going Where?*  
[http://www.nextstepincare.org/Caregiver\\_Home/Leaving\\_the\\_Hospital](http://www.nextstepincare.org/Caregiver_Home/Leaving_the_Hospital)
- *LGBT Caregiving.*  
[http://www.nextstepincare.org/Caregiver\\_Home/LGBT\\_Guide/](http://www.nextstepincare.org/Caregiver_Home/LGBT_Guide/)
- *New York State’s CARE Act.*  
[http://nextstepincare.org/Caregiver\\_Home/NYS\\_CARE\\_Act\\_Guide/](http://nextstepincare.org/Caregiver_Home/NYS_CARE_Act_Guide/)
- *What Do I Need as a Family Caregiver?*  
[http://www.nextstepincare.org/Caregiver\\_Home/What\\_Do\\_I\\_Need/](http://www.nextstepincare.org/Caregiver_Home/What_Do_I_Need/)

### **For Health Care Providers**

- *A Family Caregiver’s Planner for Care at Home.*  
[http://www.nextstepincare.org/Provider\\_Home/Care\\_Planner/](http://www.nextstepincare.org/Provider_Home/Care_Planner/)
- *A Professional Care Coordinator’s Guide to Partnering with Family Caregivers.*  
[http://www.nextstepincare.org/Provider\\_Home/care\\_coordination/](http://www.nextstepincare.org/Provider_Home/care_coordination/)
- *Assessing Family Caregivers.*  
[http://www.nextstepincare.org/next\\_step\\_in\\_care\\_guides/62/Assessing\\_Family\\_Caregivers](http://www.nextstepincare.org/next_step_in_care_guides/62/Assessing_Family_Caregivers)

- *HIPPA Questions and Answers for Family Caregivers.*  
[http://www.nextstepincare.org/Provider\\_Home/Guides\\_HIPAA/](http://www.nextstepincare.org/Provider_Home/Guides_HIPAA/)
- *Identifying Family Caregivers.*  
[http://www.nextstepincare.org/Provider\\_Home/Identifying\\_Family\\_Caregivers/](http://www.nextstepincare.org/Provider_Home/Identifying_Family_Caregivers/)
- *Preparing Family Caregivers to Manage Medications.*  
[http://www.nextstepincare.org/Provider\\_Home/Medication\\_Management\\_Guide/](http://www.nextstepincare.org/Provider_Home/Medication_Management_Guide/)
- *Reducing the Stress of Hospitalization for Patients with Dementia and Their Family Caregivers: A Provider's Guide.*  
[http://www.nextstepincare.org/Provider\\_Home/Hospitalization\\_and\\_Dementia/](http://www.nextstepincare.org/Provider_Home/Hospitalization_and_Dementia/)
- *Referring Patients and Family Caregivers to Community-Based Services.*  
[http://www.nextstepincare.org/Provider\\_Home/Community\\_Based\\_Services/](http://www.nextstepincare.org/Provider_Home/Community_Based_Services/)
- *The First Step in Care.*  
[http://www.nextstepincare.org/Provider\\_Home/Becoming\\_a\\_Family\\_Caregiver/](http://www.nextstepincare.org/Provider_Home/Becoming_a_Family_Caregiver/)
- *What Do Family Caregivers Need?*  
[http://www.nextstepincare.org/Provider\\_Home/What\\_Do\\_I\\_Need/](http://www.nextstepincare.org/Provider_Home/What_Do_I_Need/)

United Hospital Fund. 2013. Transitions in Care-Quality Improvement Collaborative.  
<https://www.uhfnyc.org/initiatives/family-caregiving/TC-QuIC>

U.S. Department of Health and Human Services. 2003. Health Information Privacy.  
<https://www.hhs.gov/hipaa/for-professionals/faq/488/does-hipaa-permit-a-doctor-to-discuss-a-patients-health-status-with-the-patients-family-and-friends/index.html>