

New York State's CARE Act: A Guide for Patients and Caregivers



The CARE Act is not the same as the Patient Protection and Affordable Care Act (also called the Affordable Care Act, or “Obamacare.”) Although the names are alike, the Affordable Care Act is about access to care, insurance coverage, and health care system reform. The CARE Act is a law about hospital discharges.

Being a patient in the hospital can be very stressful. Your family and friends are worried, too. It helps to know what to expect so you can focus on your diagnosis (what is wrong), treatment (how to get better), and follow-up plans (what to do when you return home).

Most patients stay in the hospital just a short time. Unless the hospital staff recommends a transfer to a short-term rehab (rehabilitation) unit for further treatment, patients are discharged to home. Sometimes home health care services are arranged. While these services can be very helpful, they are for just a short while (a few days or weeks after you leave the hospital). Home health care services also may be limited. For instance, a nurse or physical therapist may visit a few times a week. Or a home care aide may spend a few hours a day helping with your personal care needs such as bathing and getting dressed.

The transition between hospital and home can be hard. It helps to have someone assist you during the transition. This person is called a “caregiver” or often a “family caregiver.” A caregiver can be a family member, friend, neighbor, or someone else you know and trust. The caregiver can help with tasks like setting up appointments, making sure you have and take the right medicines, and getting medical supplies. You may need a lot of help or just a little. Having a caregiver can make you feel more confident and sure about managing your own care.

To make the hospital discharge and transition home smoother, New York State has a new law called the CARE Act. This guide explains what the law means to patients and their caregivers. This guide also includes ways of dealing with situations not covered by the CARE Act.

What is the CARE Act?

New York State's CARE (Caregiver Advise, Record and Enable) Act is based on a law developed by AARP, a group focused on helping older adults and family caregivers. About 30 states now have laws like the CARE Act. Here are the main points you should know:

- ▶ The CARE Act requires hospitals to ask patients if they want to name a person to be their caregiver who will then be part of planning for discharge and care at home.
- ▶ As long as the patient gives consent (agrees) in writing, hospital staff can share information with the caregiver about the patient's diagnosis, treatment, and plans for follow-up care.
- ▶ Hospital staff must teach the caregiver how to help and what to do when problems come up at home.



The CARE Act is just one of many regulations and laws about what hospitals must do when discharging patients home. The CARE Act adds to, but does not replace, other federal and state requirements about how hospitals must make sure that discharges to home are safe and address all the patient's needs.

Why Was the CARE Act Passed?

Studies show that patients leaving the hospital often have trouble remembering important information, such as how to take medicines on time and in the right dose. This can lead to other medical problems. In fact, a common reason patients return to the hospital soon after discharge is because they did not understand how to take their medicines correctly. That is just one of many reasons it is good to have a caregiver help the patient transition from hospital to home. The CARE Act makes the patient's caregiver a member of the patient's care team.

What Does the CARE Act Mean to Patients?

The CARE Act applies to all patients who are:

- ▶ At least 18 years old.
- ▶ Admitted to a general hospital from the Emergency Department, or admitted to the hospital for a planned procedure (such as hip replacement surgery).
- ▶ Expected to be discharged from the hospital to home.

Beyond the CARE Act: Points to Consider



To learn more about managing a hospital stay, see the Next Step in Care guides [Hospital Admission: How to Plan and What to Expect](#) and [What Is a Hospitalist?](#)

Staff in the hospital ask patients lots of questions. These include questions about health insurance, medicines, allergies, and other medical problems. Hospital staff are also required by law to ask patients:

- ▶ Whether they have an advance directive (a form that patients sign about types of treatment they do or do not want if they cannot speak for themselves).
- ▶ The hospital must offer an interpreter to patients who cannot understand and speak English. This interpreter can help explain in the patient's language what doctors or nurses are saying.

Naming Someone as Your Caregiver



The CARE Act defines a caregiver as someone “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 CARE Act is new. **As a patient in the hospital, you will be asked if you want to name someone as your caregiver.** This caregiver must be willing and able to help you transition from hospital to home.

Here are some factors to think about when you name a caregiver:

- ▶ A caregiver should be willing to help. The caregiver should know you as a person, not a patient, and know what your home and neighborhood are like.
- ▶ A caregiver should be able to help. The caregiver should not have health problems that prevent taking care of you. He or she should also arrange to spend enough time with you, perhaps by making other plans for work or child care.
- ▶ There are no restrictions about who can be a caregiver, such as age or relationship.
- ▶ The caregiver does not have to live with you but should live or work near enough to help when needed.
- ▶ The caregiver may but does not have to be the same person as your “emergency contact,” “next of kin,” or “health care proxy” (someone you choose to make health care decisions for you if you cannot make those decisions yourself).
- ▶ For most patients, a caregiver is a close friend or family member (broadly defined). But that is not always so. A caregiver may be someone you hire and pay privately (paying the costs yourself, not through insurance).

It can be hard to decide who is best to name as your caregiver. Or you might not want to name anyone. Here are points to remember:

- ▶ You do not have to name anyone as your caregiver.
- ▶ You may worry that helping you at home will be hard for your family. Or you may think having a caregiver means you will always have to depend on someone else for care. But that is not always so. It helps to plan for any special care you may need in the transition to home.
- ▶ While in the hospital, you can change your mind and name someone else as your caregiver.
- ▶ The caregiver you name can say no for any reason.
- ▶ The hospital does not have to delay your discharge just because you have not named a caregiver
- ▶ The caregiver agrees to help only from the time you leave the hospital until you are settled into a routine at home. Your caregiver does not promise to help for more time than that.

Some people provide care to others but never think of themselves as caregivers. They may think that the word "caregiver" only refers to doctors, nurses, or paid helpers such as home care aides. But that is not so. A caregiver can be anyone the patient names to help with the transition from hospital to home.

Once you name a caregiver, hospital staff will add that person's name and contact information to your medical record. This lets staff know who to talk with about your discharge and follow-up care plans.

In the past, hospital staff may have asked you about such a person, or assumed that the person who brought you to the hospital will also help when you go home. Now the hospital is required to directly ask who the caregiver will be. The person asking about your caregiver may be a social worker, nurse, or a case manager who coordinates your discharge and follow-up plans. This may be part of an assessment of all your needs at home. Sometimes these needs are more complicated than expected when you came to the hospital.

Consent to Share Medical Information

You will be asked to sign a consent form giving hospital staff permission to share with your caregiver some or all of your medical information. This is needed to help plan your follow-up care. You can limit the shared information to just your current medical problem.



It is important to sign the consent form giving hospital staff permission to share medical information with your caregiver. If you do not sign this consent form, your caregiver cannot be included in discussions about your discharge plan. This means that he or she may not learn all that is needed to help as you transition from hospital to home.

This consent form about caregivers is new. You may be surprised since it seems natural that family members will be given information about your condition. But that does not always happen. This new consent form is a way for you to name someone who can get information about your medical condition.

You will also be asked to sign a more general form about how the hospital protects the privacy of your medical information. Some hospitals combine these into one consent form.

Letting You Know When You Will Be Discharged

As soon as it is known, hospital staff should tell you and your caregiver when you are likely to go home. This may not happen until the day before you are discharged. They should also teach you about what to do and which supplies and services to have at home. This teaching may include how to manage your medicine, take blood pressure, change bandages, give injections, help with bathing, use medical equipment, prepare special meals, arrange transportation, and other needed tasks.

It helps a lot to have a caregiver who also learns about these tasks, even more so if you are not well enough to do these tasks yourself. That way, your main job as a patient is to focus on getting better.

The CARE Act Does Not Cover All Situations

The CARE Act helps in many ways but does not cover all situations. Here are some issues you still might need to figure out:

- ▶ **More than one caregiver.** While the CARE Act is only about one caregiver, you may have two or more family members or friends who agree to share caregiving tasks. Ask hospital staff if you can name more than one caregiver. Explain why this is important to you. For instance, one person may help with your medicines but not do other tasks. That person needs to know about all the medicines you will take at home.
- ▶ **If you identify as LGBT.** Even though federal and New York State laws ban discrimination based on sexual orientation and gender identity, sometimes same-sex spouses, partners, or LGBT-identified friends are not treated with respect. While you may want to protect others from such problems, your need for a caregiver is even more important. Insist on your choice of caregiver and report any discrimination to the hospital administration.



Two facts about finances:

1) Being named as a caregiver does not add any financial responsibilities (costs you have to pay) for the patient's care, other than those that now exist.

2) Being named as a caregiver does not mean you will be paid for providing care.

- ▶ **No caregiver.** Do not ignore the question about a caregiver even if you cannot think of anyone to ask for help in your transition from hospital to home. Perhaps the hospital social worker can tell you about a local community agency that can help.

What Does the CARE Act Mean to Family Caregivers?

For those who are caregivers, there are a lot of important points for you in the CARE Act. You may have a lot of experience helping an ill family member or friend, even though you never thought of yourself as a caregiver. Or this could be the first time you are called a caregiver. Maybe this is the first time your family member knows that he or she could use your help.

If you have been providing care to someone for months or even years, you know what is involved. You may even have been with this person during a hospitalization. If so, you have a lot of experience. But this hospitalization may add new and even more challenging responsibilities, at least for a while after discharge. A good way to start is by talking with your family member about why it is important to now choose a caregiver. Explain that hospital staff can talk with your caregiver about the transition from hospital to home.

Here is more to know about what the CARE Act means to family caregivers:

- ▶ **If you are caring for someone with cognitive impairments. Tell the hospital nurse or social worker if it is hard for your family member to understand and answer questions about naming a caregiver or consenting to share information.** Your family member may be even more confused because of illness, pain, or the stress of being in the hospital. You might suggest to the social worker or nurse that it would help to meet with the patient in a quiet space. You might also suggest that he or she speak with a calm voice, use short sentences and familiar words, and sit in front of and at the same level as the patient.
- ▶ **If you are caring for someone who identifies as LGBT, or identify as LGBT yourself.** The unfortunate fact is that you may meet some disrespectful hospital staff. Maybe they do not acknowledge you as the caregiver, let you visit the patient, or share information with you as the CARE Act requires. Be firm and persistent, letting staff know that

hospitals are prohibited by law from discriminating based on a person's sexual orientation or gender identity. In extreme cases, you can file a complaint with the hospital administration or a government agency. For even more information, read the Next Step in Care/SAGE [Guide to LGBT Caregiving](#).

- ▶ **If you have concerns about being a caregiver** it helps to know that being a caregiver is just for a short while—from the time a patient starts getting ready to leave the hospital until he or she is settled at home, with or without outside help. As the caregiver, you might not have enough time for your job, childcare, or other responsibilities. You may want to find others who also can help, such as family members, friends, neighbors, or a home health care agency. Find out if your family member can get home health services through Medicare, Medicaid, or private insurance. **Even though you are the caregiver, the hospital should arrange a safe discharge, which may include a referral to home health care or other community services.**

What Does the CARE Act Require that Hospitals Do For Caregivers?

The hospital must inform caregivers as soon as possible about the time of a patient's discharge. But this may not happen until the day before discharge. As soon as the patient's health seems stable (getting better, or at least not getting worse), talk with hospital staff about options for discharge. This may be being discharged to home or first going to a short-term rehab (rehabilitation) unit in a nursing home. To learn more about options for discharge, read The Next Step in Care guide [Leaving the Hospital and Going Where?](#)

If the patient is being discharged home, the CARE Act requires that hospital staff teach the caregiver about needed tasks.

These can include managing medicines, doing wound care, and using medical equipment. This teaching should start as soon as possible but no later than 24 hours before the patient is discharged. The CARE Act does not say who must teach this information, or how. Some hospitals offer videos or written material. Others may have classes or group training. Or a nurse or therapist might teach these tasks just to you. **Ask about the kind of training you need and will get.** It is good to get started at least one or two days before discharge as there is so much to do when the patient leaves the hospital. Feel free to ask staff a lot of questions, suggest specific ways to help, and tell you about referrals and other needed resources.

Learn more about what to expect at discharge in The Next Step in Care [Hospital-to-Home Discharge Guide](#).



The teaching you get in the hospital is a good way to get started. But you will likely need more guidance, perhaps from a home health nurse or doctor's office. Find out who to call if you have any problems or questions after your family member gets home.

Everyone can help make the CARE Act a success. Here are some ways:

As a patient, it is best to give a lot of thought to who you want as a caregiver before you need one. But even if you haven't done that, try to think about who would be the best person to help you when you get home.

As a caregiver, work closely with hospital staff to plan a safe discharge home. You can help by asking questions, taking notes, and sharing information about the patient's home situation that might affect the discharge. **Be honest about how willing and able you are to provide all needed care.** Tell the hospital staff if you have other responsibilities, any health problems of your own, or worries about doing some of the care needed at home.

The goal of the CARE Act is a safe and well-planned transition from hospital to home. It takes a team to do this well. This team not only includes hospital staff but also patients and their caregivers.

To learn more:

- ▶ For a one-page summary of the CARE Act requirements for patients and caregivers, see http://nextstepincare.org/Caregiver_Home/NYS_CARE_Act_Guide/.
- ▶ To read more family caregiver guides, go to UHF website [Next Step in Care](#).

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