

A Commonsense Solution to Help Family Caregivers

The Caregiver Advise, Record, Enable (CARE) Act

**Evelyn Liebman
Associate State Director, AARP New Jersey**



AARP & Caregivers

AARP is a nonprofit, nonpartisan organization, with a membership of more than 37 million, that helps people turn their goals and dreams into real possibilities, strengthens communities and fights for the issues that matter most to families such as healthcare, employment security and retirement planning.

Families are the bedrock of our healthcare system, especially for long term care.

People 50-plus represent the largest segment of those needing and almost half of those providing care.



NJ's Caregivers – A Snapshot

- **1.12 million caregivers in New Jersey.**
- **Provide more than one billion hours of care each year.**
- **Unpaid contribution to our healthcare system = \$13.6 billion a year.**
- **“Average” caregiver is a 49 year old woman working outside the home.**
- **Provides nearly 20 hours per week providing care.**
- **More than 8 in 10 caregivers are caring for a relative or friend age 50 or older.**



Our Loved Ones Want to Live at Home

- The vast majority of older Americans want to live independently at home.
- Most seniors who receive assistance at home rely exclusively on unpaid family caregivers for help.
- 78% of NJ residents age 40 and older believe that being cared for at home with caregiver assistance is the ideal situation when the basic tasks of life become more difficult due to aging or illness.
- Over half of NJ residents age 40 and older have provided care on an unpaid basis for an adult loved one who is ill, frail, elderly or has a disability.
- About half (48%) of NJ voters think it is at least somewhat likely they will be a caregiver for a relative or friend in the future.

Home Alone

Family Caregivers Providing Complex Chronic Care

- Family Caregivers Perform Complicated Medical/Nursing Tasks
- Caregivers Are Responsible for Complex Medication Management
- Training Is Limited for Often Challenging Wound Care
- Family Caregivers Feel They Have No Choice
- Most Care Recipients Do Not Receive Home Visits by Health Professionals
- Family Caregivers Often Serve as Primary Care Coordinators
- Quality of Life Is Affected



Home Alone

Family Caregivers Providing Complex Chronic Care

- **Nationwide, almost half of family caregivers perform medical or nursing tasks for their loved ones with multiple chronic physical and cognitive conditions.**
- **72% of family caregivers in NJ report performing medical and nursing tasks when caring for a loved on at home.**
- **Three out of four caregivers who provide these medical or nursing tasks manage medications, including administering intravenous fluids and injections.**
- **Most family caregivers report they receive little or no training to perform these tasks.**



Improving Transitional Care - from Hospital to Home – is Critical to Reducing Costly Re-Hospitalizations and Improving Health Outcomes

- **1 of every 8 Medicare beneficiary who leaves the hospital is readmitted in 30 days.**
- **NJ is home to some of the highest health care costs in the nation.**
- **Medicare alone reports spending \$17.8 billion a year on patients whose return trips to the hospital could have been avoided.**
- **Hospitals are penalized with a cut to their Medicare payments if these avoidable readmissions continue to occur.**
- **98% of NJ's hospitals will be penalized during the third year of the program.**

The Caregiver Advise, Record, Enable (CARE) Act of 2014

- Recognizes the changing nature of health care and the critical role family caregivers play in keeping their loved ones out of hospitals.
- Requires a hospital patient be provided with the opportunity to designate a family caregiver in the medical record.
- Requires the family caregiver be notified when their loved one is discharged.
- Requires the hospital provide an explanation, either live or by video instruction, of the medical tasks – such as wound care, injections, medication management – that the family caregiver will perform at home.



How the CARE Act Works: Designation

- Applies to patients admitted to acute care hospitals.
- Patient, or the patient's legal guardian, must be given an opportunity to designate a caregiver prior to discharge.
- Caregiver's name is placed in the medial record.
- **A caregiver is any individual designated as a caregiver by a patient who provides after-care assistance to a patient in the patient's residence. The term includes, but is not limited to, a relative, spouse, partner, friend, or neighbor who has a significant relationship with the patient.**
- Patient, or patient's legal guardian must consent to release of medial records.
- Patient may elect to change the patient's designated caregiver at any time.



How the CARE Act Works: Notification



- Caregivers are required to be notified by the hospital, as soon as possible, when the patient is being discharged to another facility or being released home.
- Lack of contact with the designated caregiver shall not interfere with, or otherwise delay the discharge of the patient.
- If the hospital attempts to contact the caregiver and s/he is unavailable, the hospital must document the attempt in the patient's records.

How the CARE Act Works: Consultation

- Prior to discharge hospital must consult with designated Caregiver.
- Provide a discharge plan that describes after care assistance tasks, if any, necessary to maintain the patient's ability to reside at home.
- Contact information for any health care, community resources, and long-term services and supports necessary to successfully carry out the discharge plan.
- Contact information for a hospital employee who can respond to questions about the discharge plan



How the CARE Act Works: Education

- Instructions in all after-care assistance tasks described in the discharge plan.
- Training & instruction for caregivers may be conducted in person or through video technology, at the discretion of the caregiver.
- Any training and instructions provided to a caregiver must be provided in non-technical language, to the extent possible.
- Instructions must include:
 - A live or recorded demonstration of the tasks;
 - The hospital designee providing the training, and who is authorized to perform the after-care tasks, must do so in a culturally competent manner and pursuant to the hospital's requirement to provide language access services under state and federal law;
 - An opportunity for the caregiver to ask questions;
 - Answers to the caregiver's questions must be provided in a culturally competent manner.
 - Instructions must be documented in the patient's medical record.

Limits Under the CARE Act

- Advanced Directives supersede the CARE Act
A patient may designate a caregiver in an Advance Directive
- The CARE Act does not establish or create a right to sue a hospital.
- A hospital is not liable for the services rendered by a caregiver.
- A Caregiver cannot be reimbursed for after-care assistance provided under the CARE Act.

Feedback

AARP wants to know how the CARE Act is working for caregivers and your loved ones.

Share your story with AARP and other caregivers:

<https://act.aarp.org/iheartcaregivers/stories/submit/>



Contact NJ Department of Health if you encounter problems:

<http://www.nj.gov/health/feedback.shtml>

What Else is AARP Doing to Support Family Caregivers?

Earned Paid Sick Leave:

Allows caregivers who work a minimum number of earned sick days for the purpose of caring for her/himself or a loved one.

Caregivers' Tax Credit:

Provides a state income tax credit to qualified residents who pay or incur certain expenses for the care of a senior family member living with the caregiver.



Nurse Delegation:

Allows nurses to delegate medication administration to certified home health professionals allowing more widely available, safe and flexible care for persons in their own homes.

Questions & More Information

Evelyn Liebman

New Jersey Associate State Director for Advocacy

Email: ELiebman@aarp.org

609-452-3906