

FUTURE OF NURSING™

Campaign for Action



Nurse Leaders in Action: Supporting Family Caregivers Through the Care Act

Webinar Summary

October 6, 2016

Home Alone: Family Caregivers Providing Complex Chronic Care is the first nationally representative population-based online survey of 1,677 family caregivers to determine what medical/nursing tasks caregivers perform, which are complex tasks usually performed in a hospital. AARP Public Policy Institute and the United Hospital Fund undertook the research and writing of this landmark report, which reveals the lack of training and support for family caregivers and the impact on their lives. This report led to the Care Act legislation, that addresses the need for instruction and support for family caregivers. Currently 33 states have adopted the Care Act.

Presenters:

Susan C. Reinhard, PhD, RN, FAAN, Senior Vice-President and Director, AARP Public Policy Institute and Chief Strategist, Center to Champion Nursing in America

Elaine Ryan, MPA, Vice President, Government Affairs State Advocacy and Strategy Integration, AARP

Nancy Holecek, MHA, RN, Senior Vice President of Patient Care Services and Chief Nursing Officer, RWJF Barnabas Health. Susan S. VanBeuge, DNP, APRN, FAAN, Associate Professor in Residence, University of Nevada Las Vegas School of Nursing



Susan Reinhard, Senior Vice President and Director, AARP Public Policy Institute and Chief Strategist, Center to Champion Nursing in America

Goals:

- Learn how the Caregiver Advise, Record, and Enable (CARE) Act is designed to ensure that family caregivers are well equipped to take care of their loved ones. Family caregivers are increasingly providing complex care at home with little to no training, which can lead to readmission of the person they care for.
- Learn why nursing leaders support it,
- Hear how the nursing community can be a vital partner in bringing the CARE Act to additional states.

During this webinar, AARP thought leaders and nursing leaders from around the country convened to talk about nurses supporting family caregivers. The CARE Act is designed to ensure that family caregivers are well equipped to take care of their loved ones. Family caregivers are increasingly providing complex care at home with little to no training, which can lead to readmission of the person they care for. Nursing leaders support CARE, and the nursing community can be a vital partner in bringing the CARE Act to all 50 states.

There is a large economic value to the services caregivers give to those they help.



In 2013, the astounding estimated value of caregiver unpaid services was \$470 billion, said Ryan of AARP, close to the annual sales of the largest retail store Walmart at \$477 billion in sales and more than Medicaid expenditures at \$449 billion.

Growing Complexity of Care

The landmark caregivers report, **Home Alone: Family Caregivers Providing Complex Chronic Care**, released four years ago was the first comprehensive study of caregivers and their impact on the care of those unable to care for themselves. It was written and researched by Susan Reinhard of AARP, Carol Levine, MA. Of the United Hospital Fund and Susan Simis MPA of the United Hospital Fund.

The report was a partnership between the AARP Public Policy Institute and the United Hospital Fund and was funded by The John A. Hartford Foundation.

It was the first in-depth national survey of family caregivers and documents what medical/nursing tasks family caregivers do; what they find difficult; who trains and guides them and the impact on their quality of life.

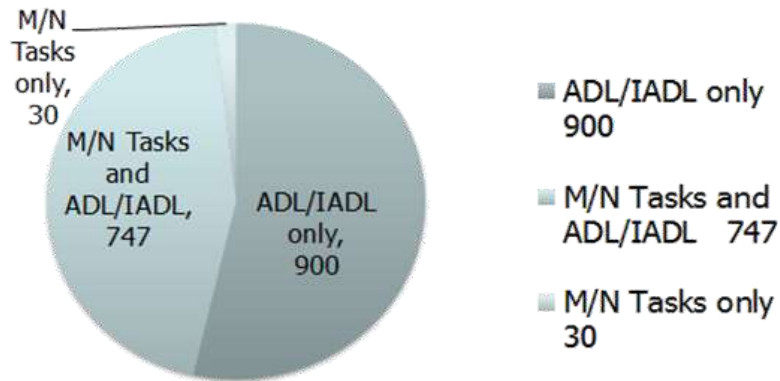


This study includes an online survey of 1,677 family caregivers to determine what medical/nursing tasks they perform. The study challenges the common perception of family caregiving as personal care and household chores that most adults already do and can easily master. However, the role of family caregivers has dramatically expanded to include complex tasks once only performed in hospitals.

The report reveals the lack of support and training family caregivers receive and how that affects their quality of life. There are ten recommendations including establishing a consensus-building body to revisit measures used to define what caregivers do.

Reinhard said Almost Half of Caregivers Perform Medical/Nursing Tasks

- ✓ 46% of the caregivers in the panel performed medical/nursing (M/N) tasks



Almost all of medical/nursing caregivers (96 percent) also provided ADL or IADL assistance.

Medical/Nursing Tasks

- ✓ Managing complex medications (Poly meds, Injections)
- ✓ Preparing special food diets
- ✓ Wound care
- ✓ Changing catheters
- ✓ And more...



IN THEIR OWN WORDS:

“He’s been in the hospital about 18 times over the past two years. Leaving the hospital the first time was particularly scary because he came home with drains from his wounds. They had to be cleaned frequently. I had a few lessons in the hospital but I wasn’t prepared for doing it myself when we came home. I knew the procedure but nothing prepared me for seeing his open wound and having to clean it. I was scared, really scared.” -Jackie (cares for her husband)

Research Leads to Legislation

Based on the *Home Alone* report, AARP and other state offices began advancing legislation known as **The Caregiver Advise, Record, Enable (CARE) Act**, that focuses on instruction and support for family caregivers. There are 33 states so far which have adopted the law. Ryan said there are 17 states ready to move to adoption in 2017

It focuses on hospital admissions and discharges as an important first step in dealing with caregivers' needs.

As Ryan of AARP notes there are three major provisions of the CARE Act:

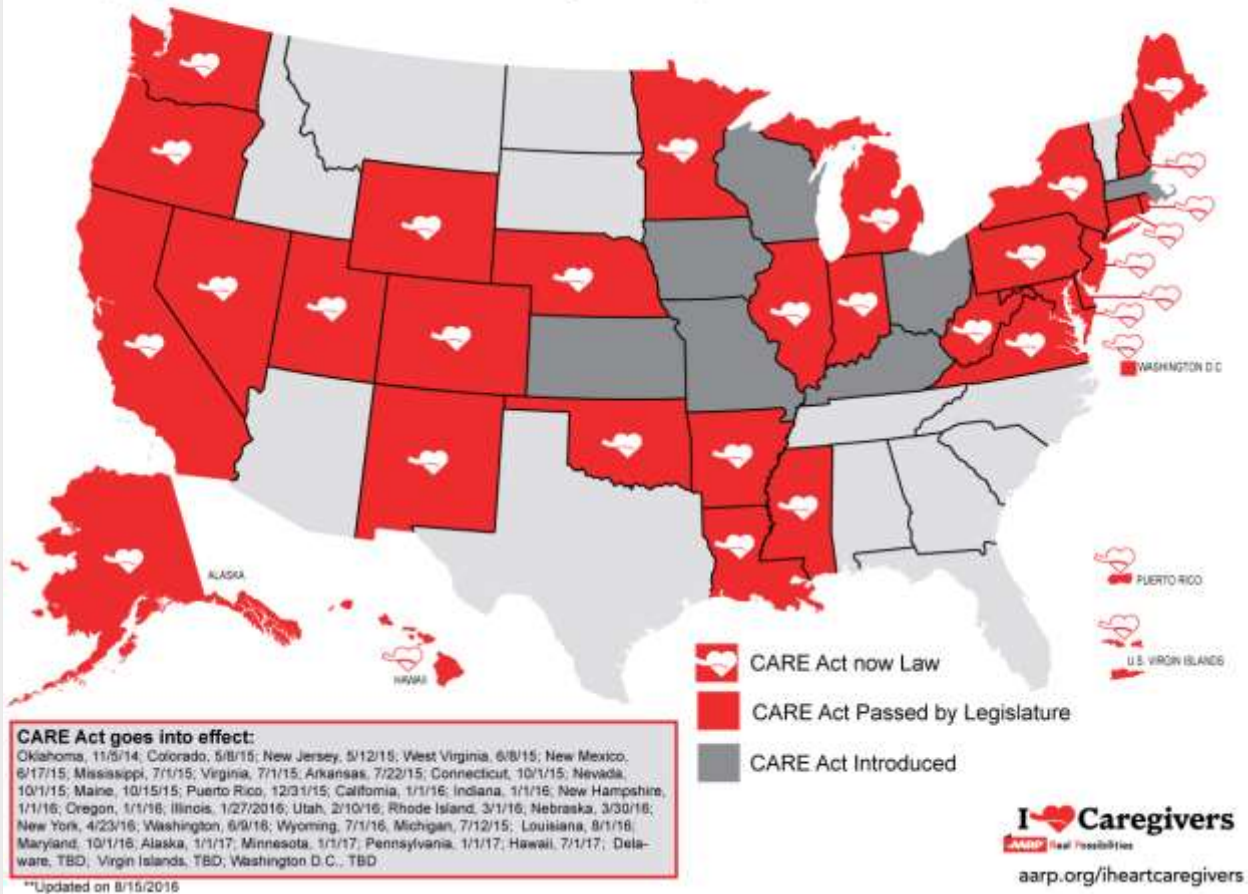
- **Provision #1: Designation**
 - Give hospital inpatients the chance to name a caregiver and have their information put in the record
- **Provision #2: Notification**
 - Contact the caregiver prior to discharging the patient
- **Provision #3 Instruction**
 - Consult with the caregiver and provide a demonstration and a chance to ask questions about the tasks the caregiver will need to carry out at home.



The following map shows each state and where they are in the process of adopting the CARE law:

The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.



Care Act: What Next?

✓ We need a broad education and outreach campaign to inform:

- Consumers
- Hospitals
- Other stakeholders

✓ We need state-specific efforts to ensure implementation:

- Regulatory work
- State oversight
- Hospital processes and best practices

Other State Advocacy to Support Family Caregivers

- ✓ Workplace Flexibility, paid and unpaid leave, respite
- ✓ Expand options for care—nurse scope of practice, delegation, Registry, Telehealth
- ✓ Improvements to state Home and Community based Services (HCBS) systems
- ✓ Financial and Legal Solutions---Uniform Guardianship Act, Improvements to Guardianship System. Uniform Power of Attorney.Caregiver Tax Credits

National Scan

- Conduct a national review and scan of Hospital CARE Act implementation processes. As Reinhard notes, we must help hospitals duplicate promising practices, better ways to train and capture innovation in the field,
- Develop a snapshot of implementation in the state
- Produce publications featuring overall promising practices

How are you? How are you managing?

Are the two most important questions to ask a patient. says Susan Reinhard.

What Nurses are Saying...

"The CARE Act came at a good time and aligns with the overall changes in healthcare: HCHAPS, Value based purchasing, need to reduce readmissions, CMS meaningful use. The CARE Act put **glue** to these things."

"This is a paradigm shift – from emergency contact to caregiver"

Home Alone Alliance

- ✓ It's critical to form an alliance of private, non- profit, and academic organizations to further the Care Act, said Reinhard.
- ✓ Change the field, change the culture
- ✓ Provide quality training videos for family caregivers performing complex tasks

Family Caregiver Instructional Videos

- ✓ Tools for preparing family caregivers providing medical/nursing tasks
- ✓ Audience: Family Caregivers and Nursing Students
- ✓ First series focuses on medication management

AARP and the coalition will produce videos to help families understand how to perform specific tasks for their loved ones after they bring them home from the hospital.

The first video will focus on medication management, how to read labels and when to give medications and in what doses.

How Are You?

How Are You Managing?

Are the two most important questions to ask each patient. The answers will illicit responses that can help with care

Pilot Series

There are a number of videos AARP will produce to educate family caregivers on how to perform various tasks. The first one is on medications. Family Caregiver Video Guide to Managing Medications www.aarp.org/nolongeralone



Recognition and Support from Healthcare Professionals

- Better communication
- More preparation for transitions across settings
- Assessment of the caregivers' needs

Rarely are family caregivers asked “**How are *you* doing? How are *you* managing?**”

- Recognition as “team member”
 - intimate knowledge of care recipient
 - Acquired care skills
 - Desire to be partners



Susan VanBeuge, DNP, APRN, Associate Professor in Residence, University of Nevada Las Vegas School of Nursing.

VanBeuge said “hospitals have embraced it (Care Act) and the community has embraced it, referring to the testimony nurses gave in the legislature during Nurses Day.

“We wanted to make something good happen in our state.”

People are happier with the caregivers' training and the knowledge that people will be trained to take care of their loved ones when they leave the hospital for home.

“You can see the relief on caregivers' faces,” she said.

What they learned is that training needed to be done at the beginning of the hospital admission, not the end.

“Typically we were scrambling at the last hour. Now we know discharge begins with admission.”

Nurse leadership is critical. Of the 33 states which approved the Care Act, 22 hospital systems were supportive.



Nancy Holecek, MHA, RN Senior Vice President of Patient Care Services and Chief Nursing Officer, RWJF Barnabas Health

It’s important to educate medical staff and other organizations about the Care Act.” she said. Holecek also said staff should be provided with scripts in order to be able to answer questions from caregivers and/or patients about care after discharge from the hospital.

It’s also critical to know what services the caregiver is comfortable providing. “Sometimes a caregiver might want to give medication but not (perform) wound care.”

The following are Resources for Family Caregivers:

- www.aarp.org/caregivers
- www.aarp.org/nolongeralone
- www.aarp.org/SupportCaregivers
- www.aarp.org/lheartcaregivers

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