

NURSE LEADERS IN ACTION: SUPPORTING FAMILY CAREGIVERS THROUGH THE CARE ACT

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Real Possibilities

Today's Webinar

- 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.
- Learn why nursing leaders support the CARE Act
- Hear how the nursing community can be a vital partner in bringing the CARE Act to additional states.



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Valuing the Invaluable

Putting a Dollar Value to Family Caregiving

In 2013, about **40 million** family caregivers in the United States provided an estimated **37 billion hours** of care. The estimated value of their unpaid service was approximately **\$470 billion**.



HOW DOES FAMILY CAREGIVING COMPARE?
2013–2014 in billions

Walmart Annual Sales \$477

Family Caregiving estimated value \$470

Combined Annual Sales \$469

Apple, IBM, Hewlett Packard and Microsoft

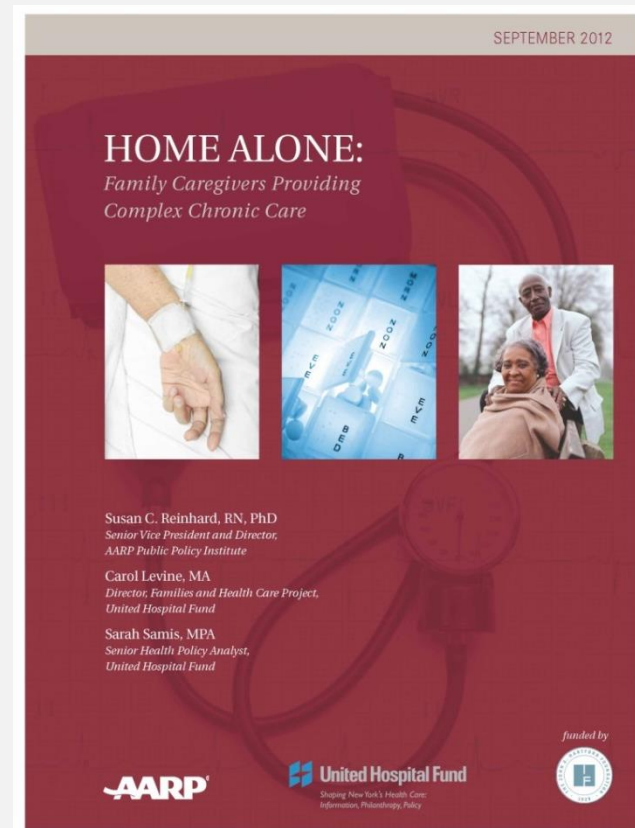
Total Medicaid Expenditures \$449

Source: *Valuing the Invaluable: 2015 Update - Undeniable Progress, but Big Gaps Remain (2015)*
AARP Public Policy Institute

Growing Complexity of Care

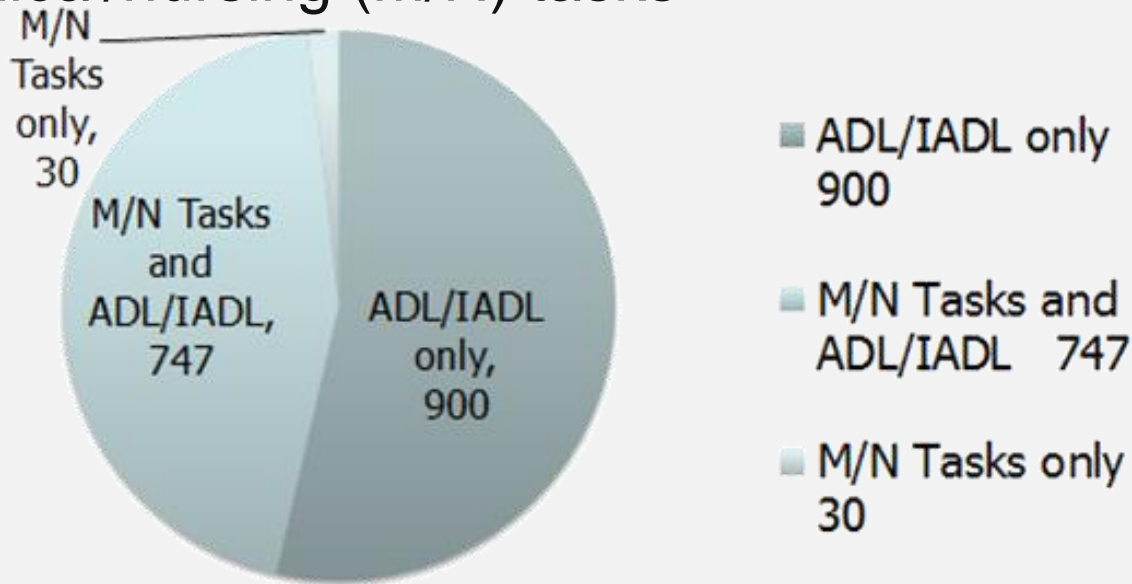
Home Alone: Family Caregivers Providing Complex Chronic Care

- Partnership between the AARP Public Policy Institute and the United Hospital Fund
- Funded by The John A. Hartford Foundation



Almost Half Perform M/N Tasks

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



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

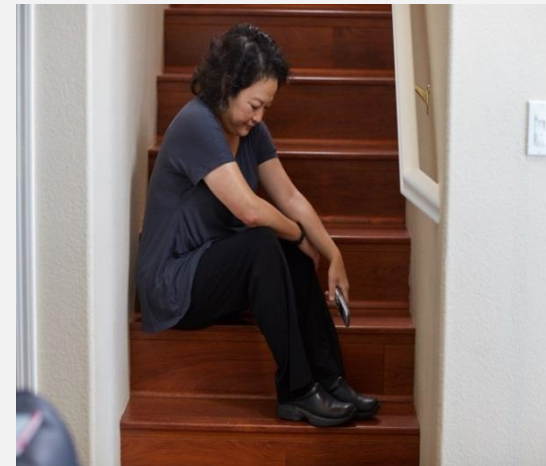
Medical/Nursing Tasks

- Managing complex medications (Poly meds, Injections)
- Prepare 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)



The Caregiver Advise, Record, Enable (CARE) Act

- **Provision #1: Designation**

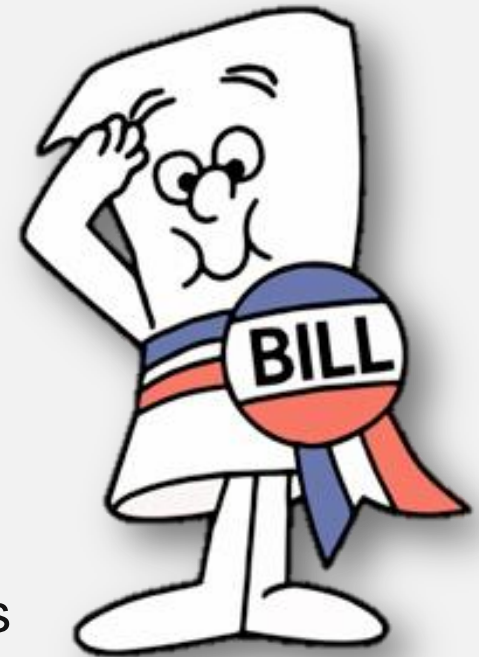
- Give hospital inpatients the chance to name a caregiver and have their information put in the record

- **Provision #2: Notification**

- Contact the caregiver prior to discharging the patient

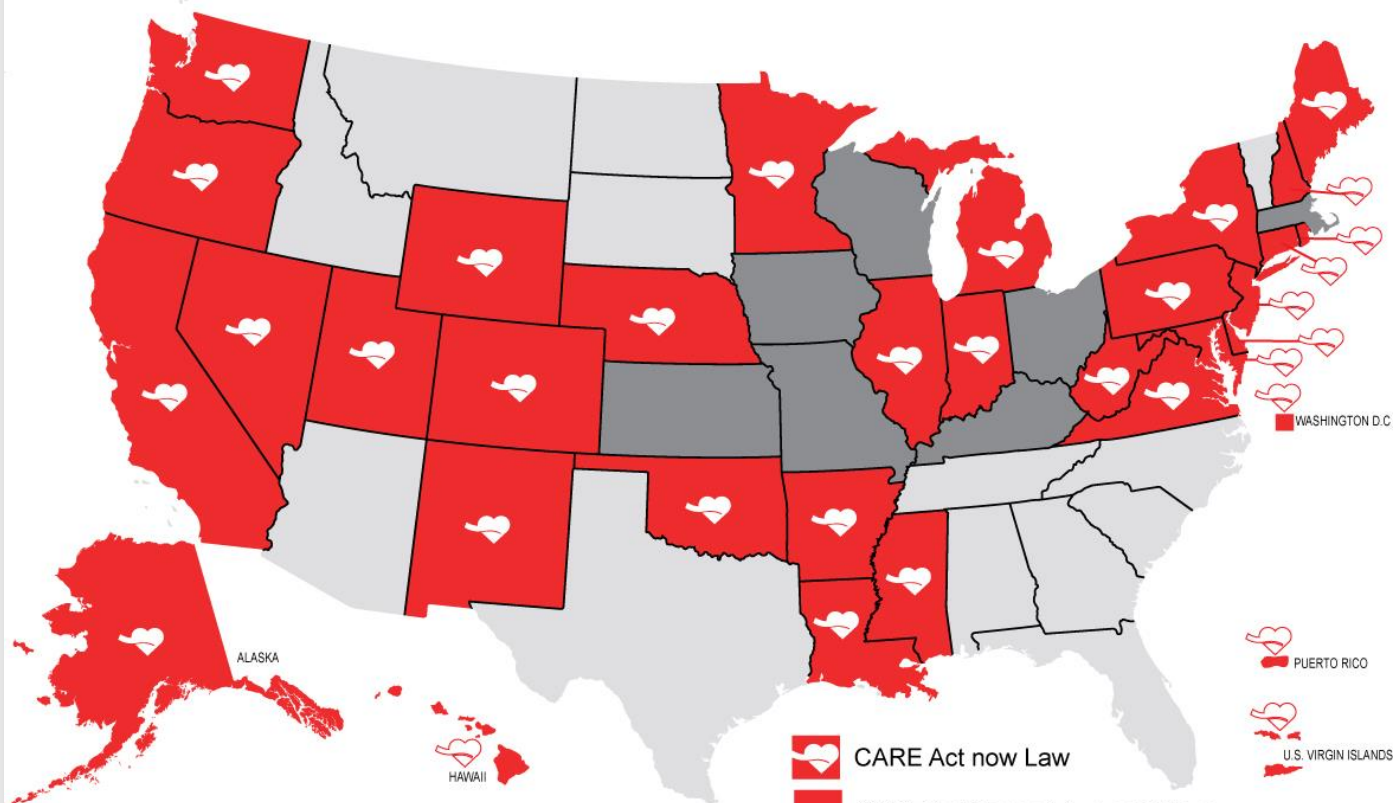
- **Provision #3: Instruction**

- 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 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 goes into effect:

Oklahoma, 11/5/14; Colorado, 5/8/15; New Jersey, 5/12/15; West Virginia, 6/8/15; New Mexico, 6/17/15; Mississippi, 7/1/15; Virginia, 7/1/15; Arkansas, 7/22/15; Connecticut, 10/1/15; Nevada, 10/1/15; Maine, 10/15/15; Puerto Rico, 12/31/15; California, 1/1/16; Indiana, 1/1/16; New Hampshire, 1/1/16; Oregon, 1/1/16; Illinois, 1/27/2016; Utah, 2/10/16; Rhode Island, 3/1/16; Nebraska, 3/30/16; New York, 4/23/16; Washington, 6/9/16; Wyoming, 7/1/16; Michigan, 7/12/15; Louisiana, 8/1/16; Maryland, 10/1/16; Alaska, 1/1/17; Minnesota, 1/1/17; Pennsylvania, 1/1/17; Hawaii, 7/1/17; Delaware, TBD; Virgin Islands, TBD; Washington D.C., TBD

**Updated on 8/15/2016

I Caregivers
 Real Possibilities

aarp.org/iheartcaregivers

CARE Act: What's Next?

- **Broad education and outreach campaign to inform:**
 - Consumers
 - Hospitals
 - Other stakeholders
- **State-specific efforts to ensure implementation:**
 - Regulatory work
 - State oversight
 - Hospital processes and best practices



Other State Advocacy to Support Family Caregivers

- Caregiver Support and Education
- CARE Act and Implementation
- Workplace Flexibility - FMLA, paid & 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

CARE Act – National Scan

- Conduct a national review and scan of Hospital CARE Act implementation processes
- Develop a snapshot of implementation in the state
- Produce publications featuring overall promising practices

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

- Alliance of private, non profit, and academic organizations
- 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

Pilot Series

Family Caregiver Video Guide to Managing Medications



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



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QUESTIONS OR COMMENTS?

Press *1 on your telephone key pad to ask a
question

OR

Use the “chat” feature to send “everyone” a
question.

RESOURCES FOR FAMILY CAREGIVERS

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