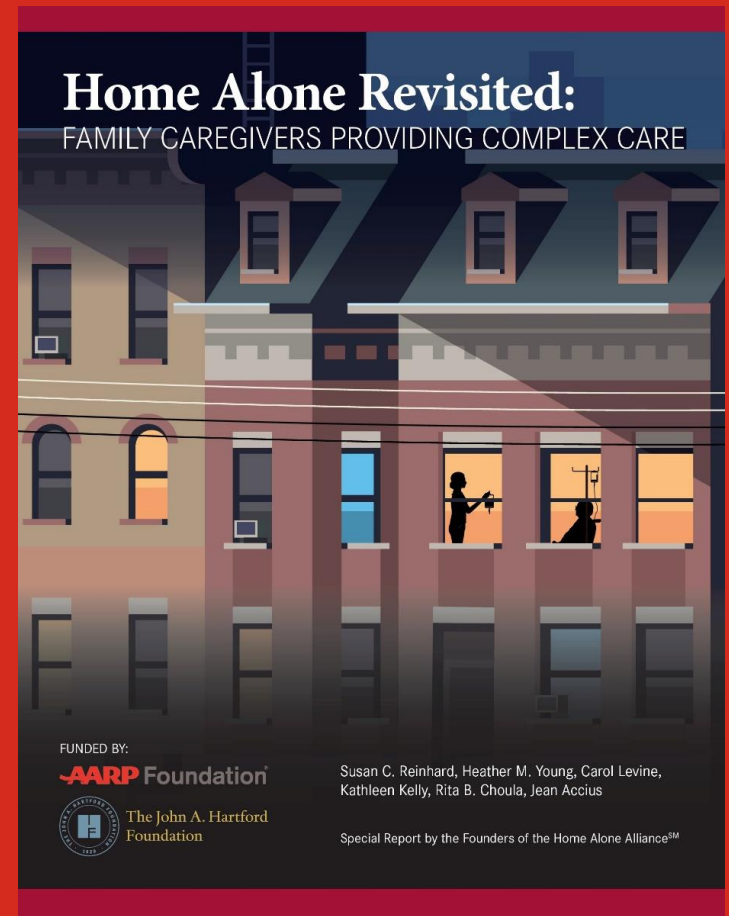


# THE FRONT LINE OF CARE: PROVIDING SUPPORTS FOR FAMILY CAREGIVERS

Elaine M. Ryan, AARP Vice  
President

November 18, 2019



Home Alone Alliance<sup>SM</sup>  
a collaborative from AARP

# Today's Agenda

- Valuing the Invaluable—Family Caregiving in the U.S.
- Home Alone Revisited: Family Caregivers Providing Complex Care
- The Cost of Caregiving
- State Advocacy Actions to Support Caregivers

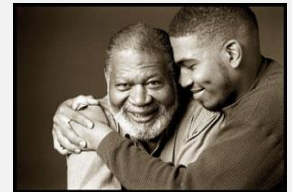
# Family Caregiving: Then

- Family caregivers traditionally provided assistance with ADLs and IADLs.
- Caregiving was an almost entirely private affair.
- Multigenerational households were more common.



# Family Caregiving: Now

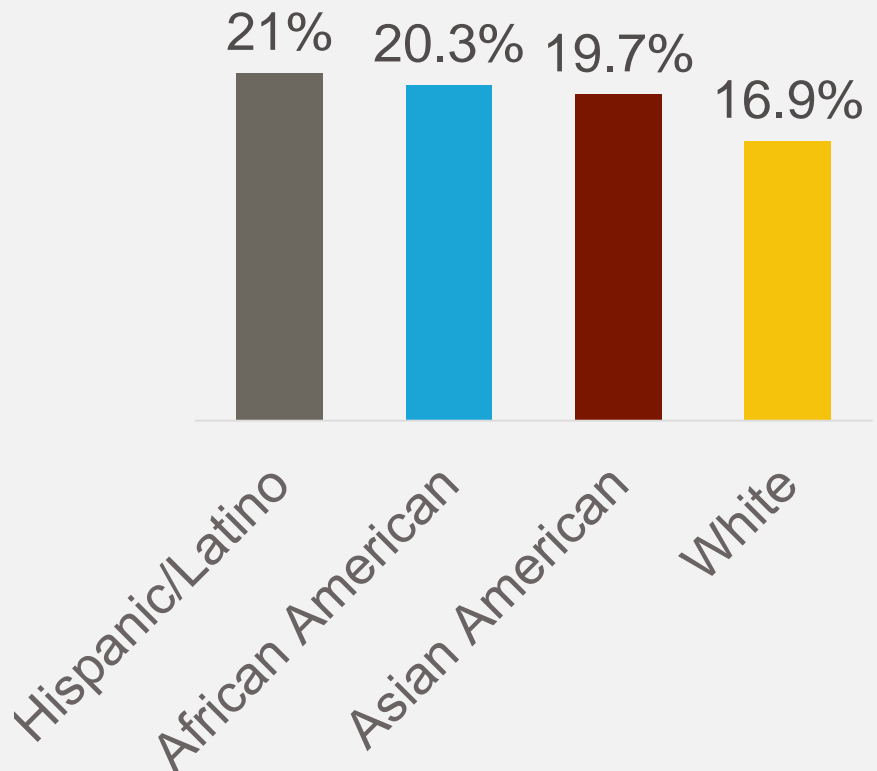
- The role of family caregivers has dramatically expanded.
- This includes performing medical/nursing tasks once only provided in hospitals.
- Smaller households and family sizes places caregiving responsibility on fewer people.
- Family caregiving is being addressed by policymakers.



# Today's Family Caregivers

- More than 40 million Americans perform the family caregiving role each year to someone age 18+.
- Family caregiving cuts across gender, age and race/ethnicity.
  - Four in ten of these family caregivers are men.
  - Multicultural groups over-index in caregiving.
  - One in four is a millennial.

Prevalence of Caregiving by Race/Ethnicity



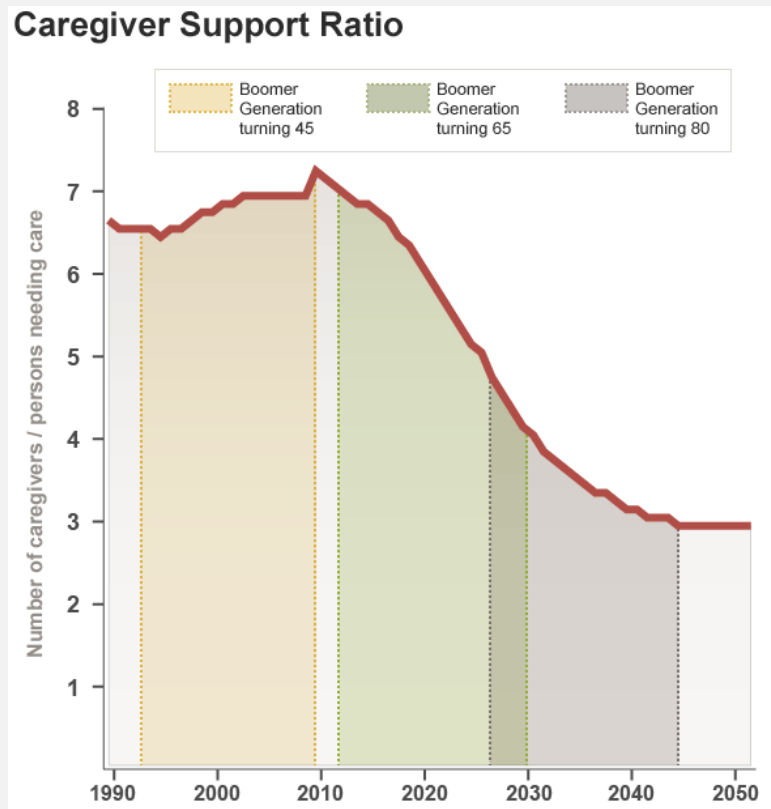
# Today's Family Caregivers

- Family caregivers today support people with various conditions, and do so in a variety of contexts.
  - Close to 1 in 3 support someone in a rural area.
  - 15% of care recipients are veterans.
  - More than half (60%) are employed.
  - 1 in 5 care for a person with a mental health or emotional issues.



# The Care Gap

- In **2010**, the caregiver support ratio was more than **7 potential caregivers** for every person in the high-risk years of 80-plus.
- By **2030**, the ratio is projected to decline sharply to **4 to 1**.
- It is expected to fall to **less than 3 to 1 in 2050**, when all boomers will be in the high-risk years of late life.





# Valuing the Invaluable

**580,000** Family Caregivers



in

**Wisconsin**



**490**  
Million Hours

Unpaid  
Family  
Care

**\$14.10**

economic  
value per hour



estimated  
economic value

**\$6.9 billion**

**AARP**

Family Caregiving™

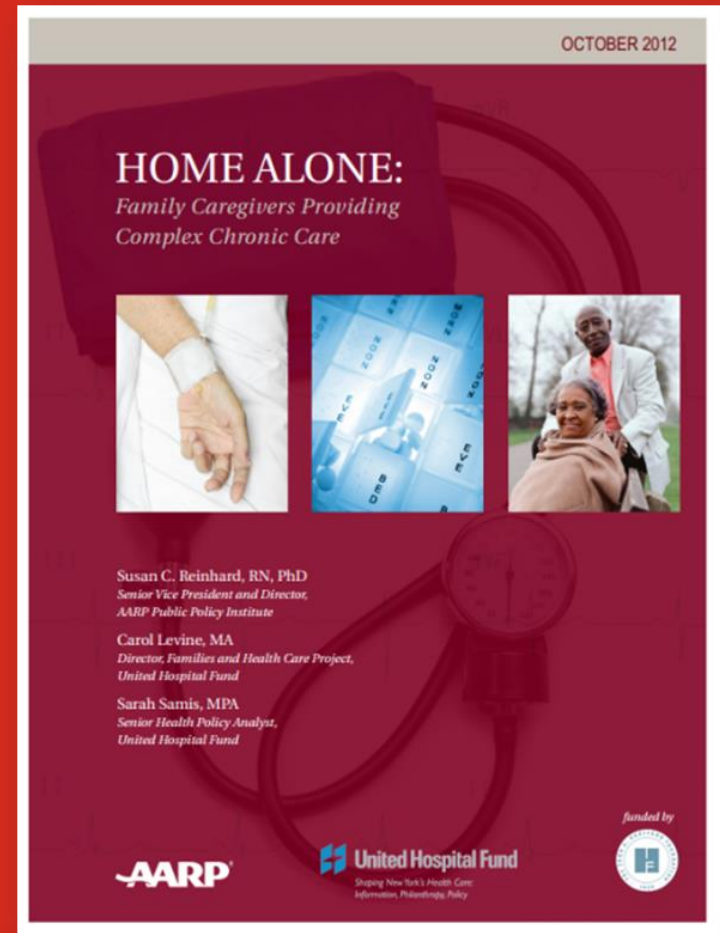
**[aarp.org/valuing](https://aarp.org/valuing)**

All estimates are for 2017 | source: AARP Public Policy Institute (2019)



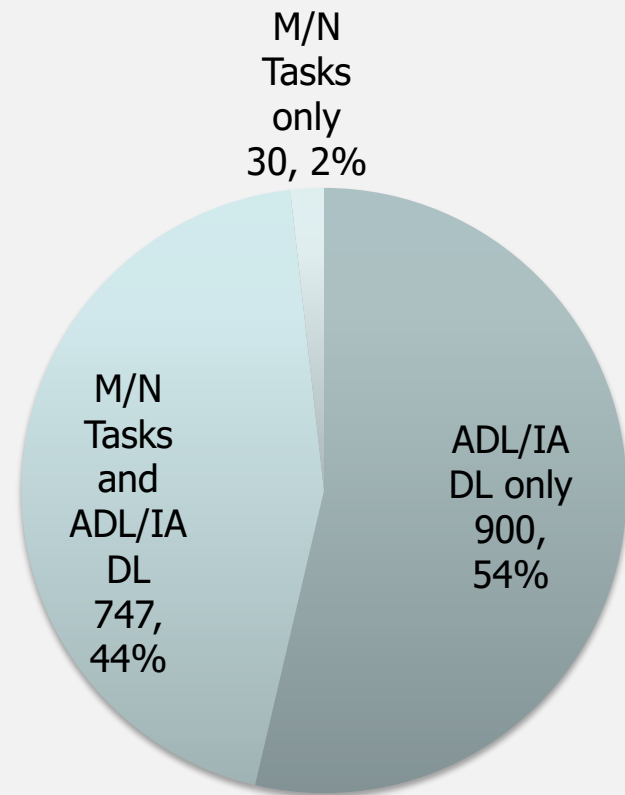
# The 2012 *Home Alone* Study: Sparking Action

Funded by The John A. Hartford Foundation



# Home Alone Findings

- 46% of caregivers performed medical/nursing (M/N) tasks
- > 96% of medical/nursing caregivers also provided ADL or IADL assistance
- 89% care recipients are adults 50+
- Many family caregivers perform these tasks with very little clinical guidance, leaving them feeling stressed and concerned about making a mistake.



# The *Home Alone Study* sparked action:

- Home Alone Alliance<sup>SM</sup>
- Caregiver Advise, Record, Enable (CARE) Act
- Family Caregiving Institute at UC Davis
- Collaborations with National League for Nursing (NLN) and *American Journal of Nursing*
- Inclusion of complex tasks in the National Academies of Science, Engineering and Medicine's study of family caregivers

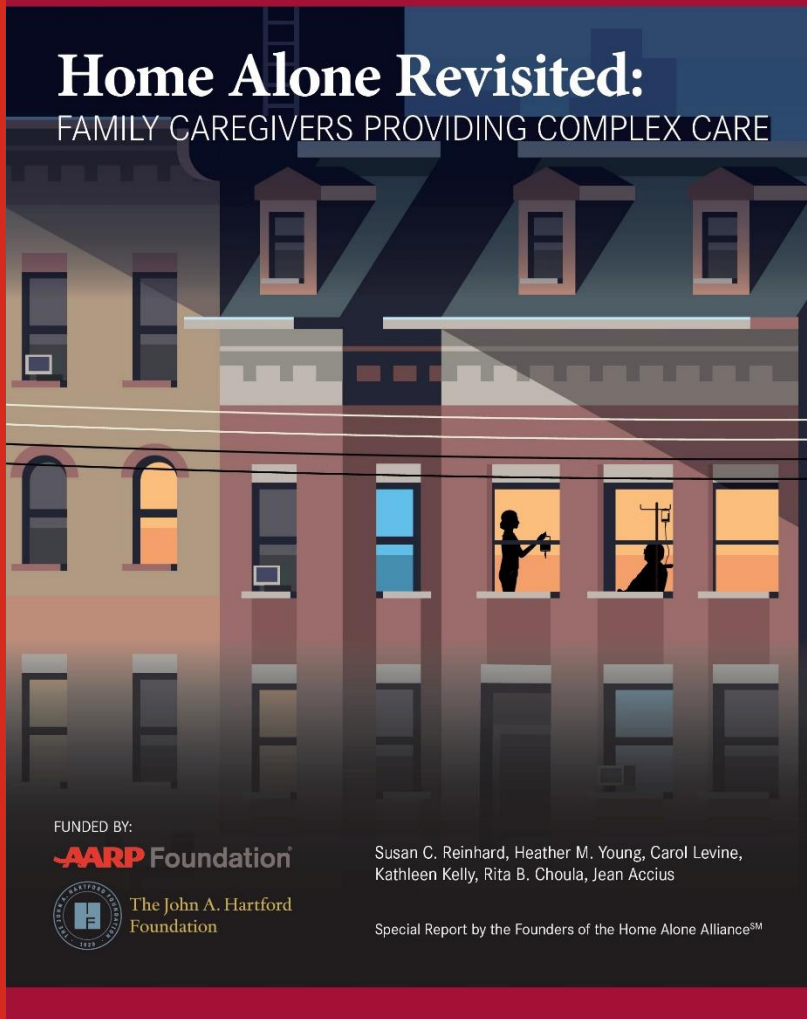
# Partnerships Among Home Alone Alliance<sup>SM</sup> Members

- **Formative Research (*It All Falls on Me*):** AARP, United Hospital Fund
- **Writing and Publishing Evidence-Based Articles:** AARP, UC Davis, American Journal of Nursing.
- **Video Production:** AARP, UC Davis, U.S. Department of Veterans Affairs
- **Outreach to Nursing Professionals:** AARP, NICHE
- **Curriculum Development for Nursing Students:** AARP, UC Davis, National League for Nursing
- **[www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone)**



# Home Alone Revisited:

FAMILY CAREGIVERS PROVIDING COMPLEX CARE



FUNDED BY:

**AARP** Foundation



The John A. Hartford  
Foundation

Susan C. Reinhard, Heather M. Young, Carol Levine,  
Kathleen Kelly, Rita B. Choula, Jean Accius

Special Report by the Founders of the Home Alone Alliance<sup>SM</sup>

*For full report, please see:*  
AARP Public Policy Institute  
[www.aarp.org](http://www.aarp.org)

# Major Findings

1. Today's caregivers provide ***intense and complex care***, including medical/nursing tasks and managing multiple health conditions that are often accompanied by pain.
2. Today's caregivers are ***diverse*** and so are their experiences.
3. Caregivers who are socially isolated or have no choice about caregiving are more ***at risk*** for experiencing difficulties with complex care.
4. Caregivers performing more medical/nursing tasks experience both ***positive and negative impact***.
5. Many family caregivers are still on their own—health systems should do ***more to prepare*** these vital members of the team.

# Finding #1: Intense and Complex Care

- 50% of family caregivers perform medical/nursing tasks for individuals with challenges in physical, cognitive, and behavioral health.
- They carry a heavier responsibility than those who do not perform these tasks, spending more than twice as many hours per week providing care.



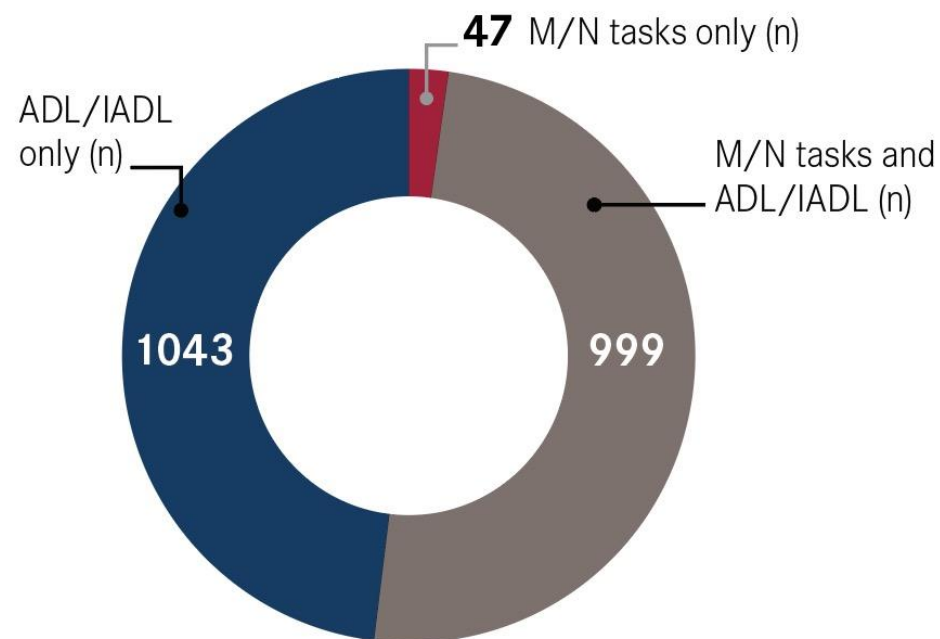


# Finding #1: Intense and Complex Care

Those who perform M/N tasks are:

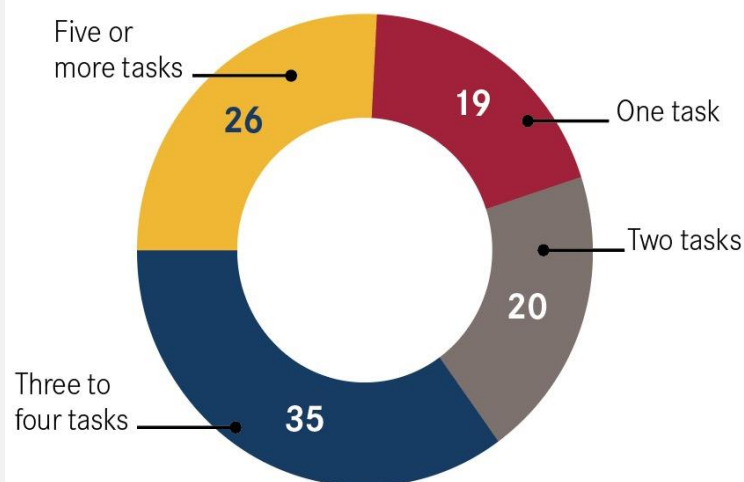
- Twice as likely to help with ADLs
- Carry a heavier load of IADLs
- Three times as likely to spend more than 20 hours per week
- More than twice as many hours providing care per week

**Distribution of Caregiving Tasks**

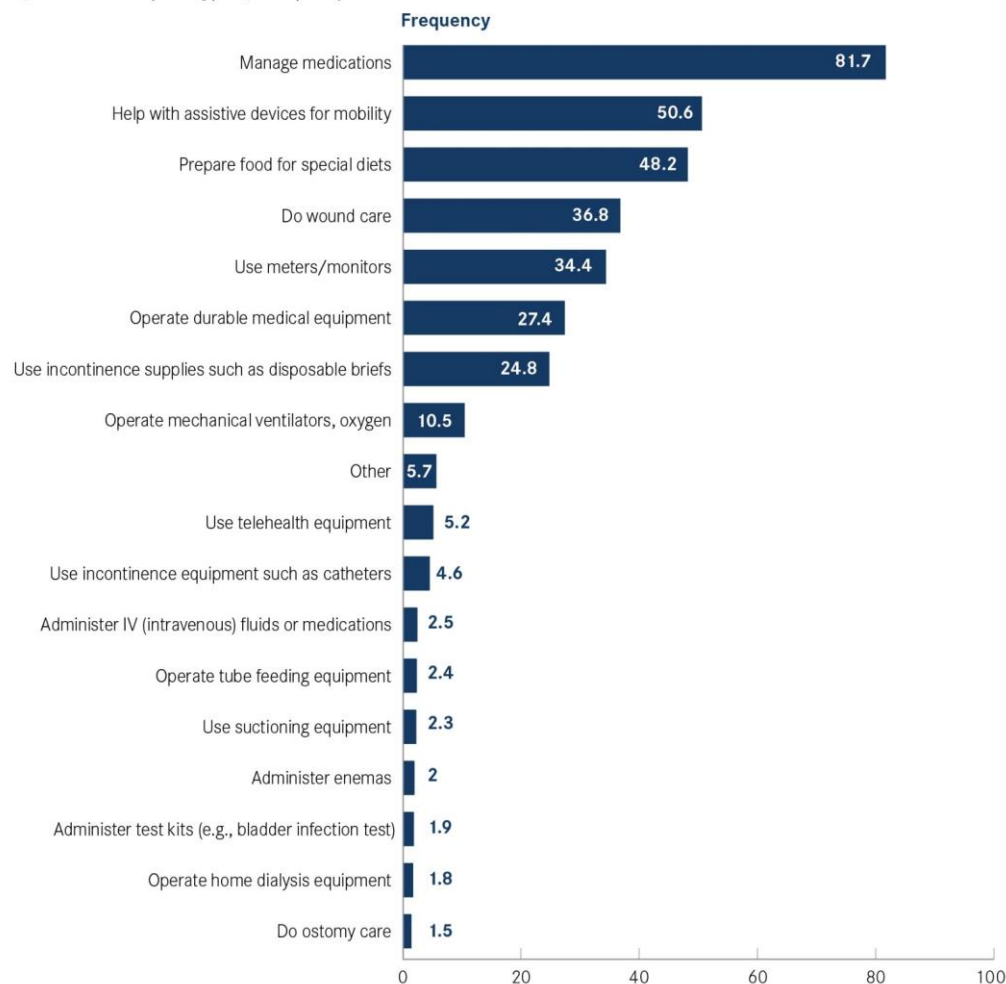


# Medical/Nursing (M/N) Tasks

**Performing Multiple M/N Tasks, %**  
(*n* = 1,084)

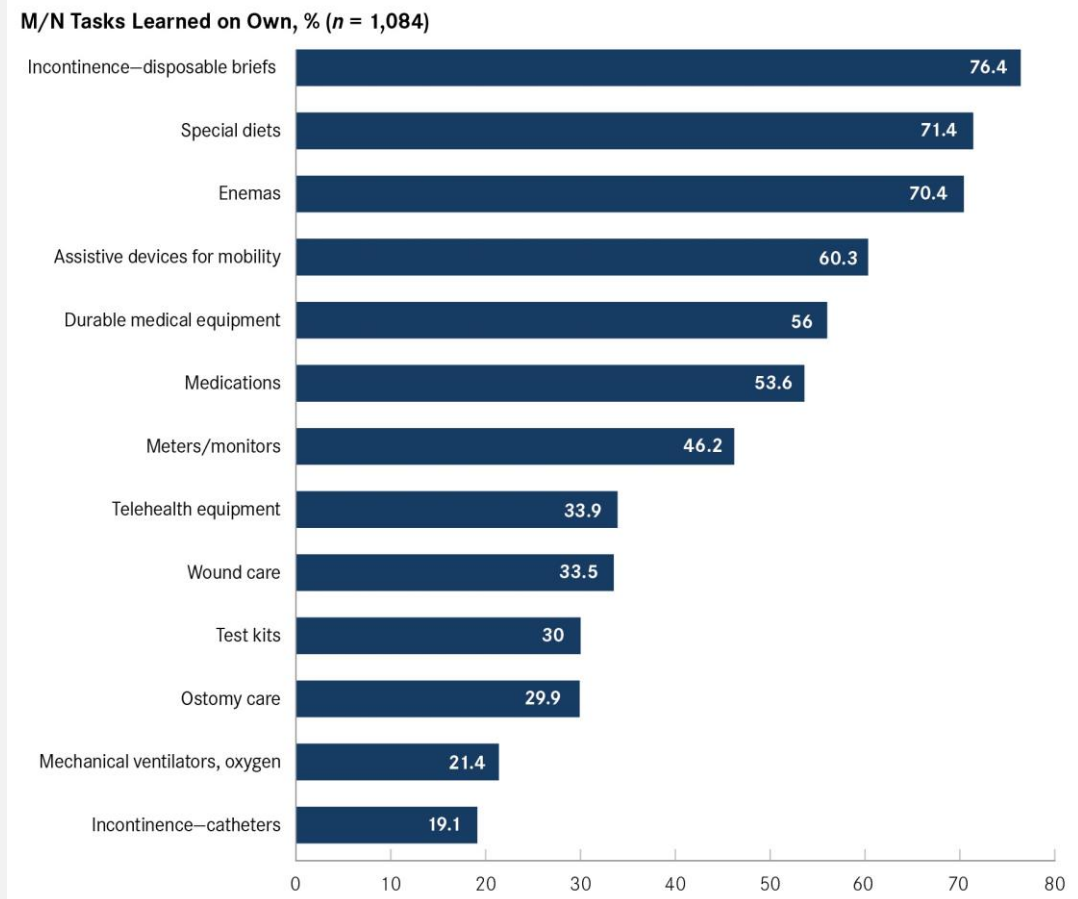


**M/N Tasks Frequency, % (*n* = 1,084)**



# Preparation to perform M/N tasks

- Most commonly, caregivers learn on their own
- Health care professionals more involved in complex, skilled tasks
- Millennials and men less likely to receive instruction



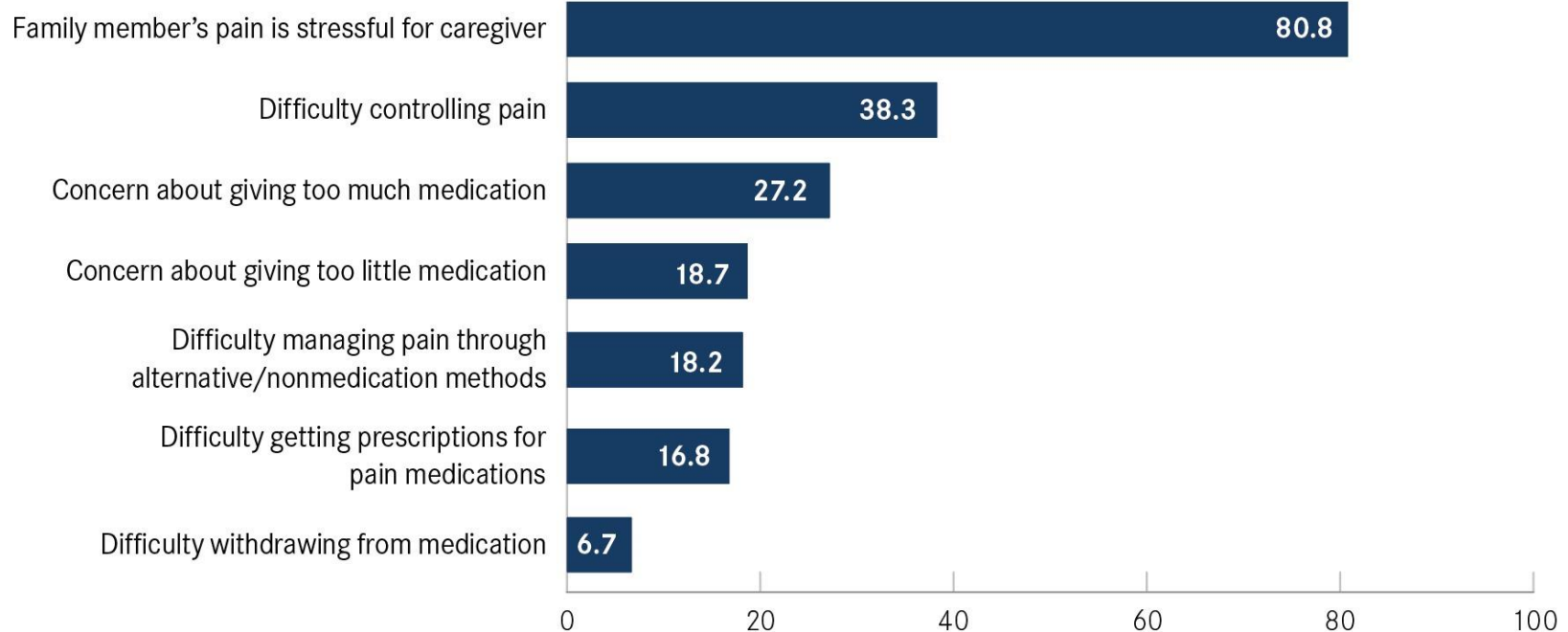
# Intense and Complex Care: Pain Management

**70%** of family caregivers who perform medical/nursing tasks face the practical and emotional strain of managing pain.

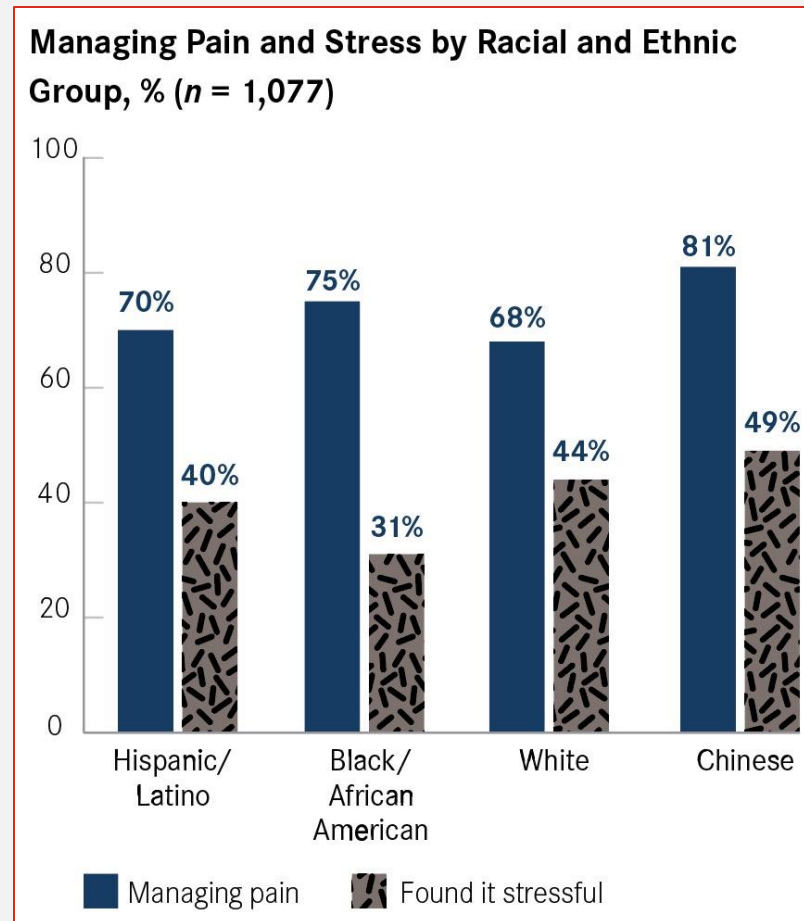
***“Just seeing my father go from being a tough man to being weak is hard to see.”***

# Intense and Complex Care: Pain Management

## Managing Pain and Discomfort, % (n = 751)



# Intense and Complex Care: Pain Management



## Finding #2: Today's caregivers are *diverse* and so are their experiences

### Caregiving:

- Cross-generational issue for both men and women
- Different age cohorts face distinct challenges for their life stage.
  - **one in four** of these caregivers is a millennial
  - **40 percent** of millennials and younger caregivers are supporting someone with a behavioral health condition.
- Multicultural family caregivers are **more likely** to experience strain and worry about making a mistake, **regardless of income.**



# Generational Differences- Negative Effects of Caregiving

Millennials and Generation X caregivers more likely than older generations to:

- Worry about making a mistake
- Worry about paying for care
- Feel an added level of stress from having to talk to so many health care professionals or suppliers
- Note that performing these M/N tasks causes problems in their relationship with the family member and makes the home feel less safe because of the equipment and supplies.

# Generational Differences – Positive Effects of Caregiving

- Boomers more likely than younger generations to feel performing M/N tasks eases their worries about their family member's condition
- More boomers and generation X caregivers than millennials feel they are making an important contribution
- Millennials and generation X caregivers are more likely than the silent generation to feel that performing these M/N tasks offers them new skills they can apply to other areas of their life

# Multicultural family caregivers

- Multicultural family caregivers are performing M/N tasks at rates similar to Whites
- The impact of income and experience with strain and worry differs quite strikingly by racial and ethnic group:
  - Multicultural family caregivers are more likely to experience strain and worry about making a mistake, regardless of their income level
  - For Whites, the level of strain and worry about making a mistake decreases as their income increases

## Finding #3: Caregivers who are socially isolated or have no choice about caregiving are more *at risk* for experiencing difficulties with complex care

- Social isolation compounds difficulties with complex care, across generations and cultural groups.
- Most family caregivers who perform medical/nursing tasks feel they have no choice.



# Social Isolation

- Millennials more likely to be disconnected from friends – 20% do not see any of their friends in a given month
- Blacks/African Americans are most at risk of being socially isolated and less satisfied with the quality of their social relationships

***“I feel bad about venting to my friends, so I end up just keeping it all inside.”***



# Social Isolation

- Family caregivers with ***fewer social connections and lower satisfaction*** with their social supports are at higher risk.
- They:
  - Experience more stress in coordinating with health care professionals
  - Are more likely to feel the pressure of constantly watching
  - Are more likely to feel they have no choice in taking on caregiving duties
  - Are more likely to perceive the tasks as difficult
  - Worry more about making a mistake
  - Experience more strain, depression, sleep disturbance, and poor health

# Choice

- Majority feel they do not have a choice in taking on M/N tasks.

## No Choice by Generation, % (*n* = 1,040)

Generation	%
Generation Z ( <i>n</i> = 19)	50
Millennial ( <i>n</i> = 207)	47
Generation X ( <i>n</i> = 240)	58
Boomer ( <i>n</i> = 498)	60*
Silent generation ( <i>n</i> = 113)	73**

\*Statistically significant compared with millennials

\*\*Statistically significant compared with boomers,  
generation X caregivers, and millennials



# Choice

- About 1/3 feel pressured by their own personal feelings, the care recipient, another family member, or a physician or nurse
- Culture or religion influenced ½ of caregivers
- Women more likely to feel pressure from other family members
- Chinese caregivers more likely to feel they have no choice and feel pressure from their families
- Blacks/African Americans and Hispanics/Latinos more likely to indicate culture or religion influenced their decision
- The older the caregiver, the less they feel they have a choice

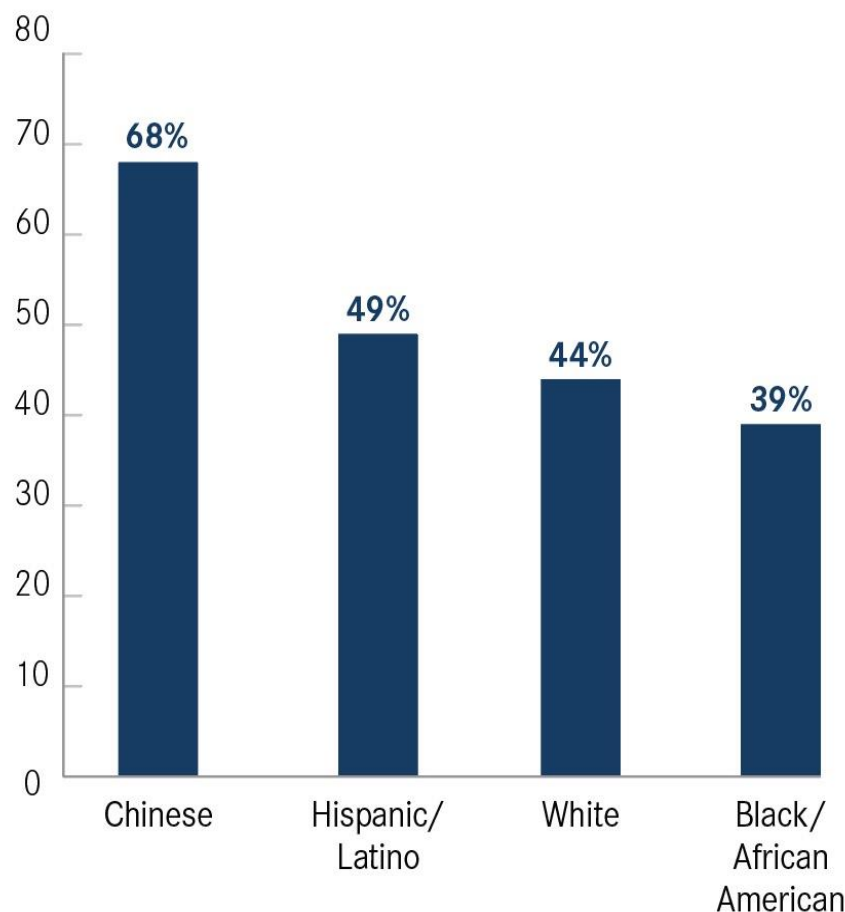
## Finding #4: Caregivers performing more medical/nursing tasks experience both *positive and negative impact*

- About half of caregivers who perform medical/nursing tasks are worried about making a mistake. The more complex the task, the greater the worry.
- Stress, worry, financial concerns, and feeling the need to be vigilant rise as the demands of providing complex care increase.
- The more medical/nursing tasks they perform, the more caregivers feel they are keeping their family member out of a nursing home.

# Worry about making a mistake

Almost half of family caregivers who perform complex care are afraid of making a mistake.

Worry about Making a Mistake by Racial and Ethnic Group, % (n = 1,077)



# Worry about making a mistake

- Caregivers who worry about making a mistake also report:
  - They constantly watch out for something to go wrong
  - They find the caregiving tasks more difficult
  - Their worry is greater in situations in which they have more instruction from health care professionals
  - Talking to multiple professionals and suppliers is associated with greater stress

# Stress, worry, financial concerns, and feeling the need to be vigilant rise as the demands of providing complex care increase

- Almost half of M/N caregivers feel down, depressed, or hopeless compared with 1/3 of caregivers who do not perform M/N tasks and 1/4 of older adults
- **Higher caregiver strain** is associated with:
  - Being younger
  - Being female
  - Providing care to a parent or grandparent
  - Caring for an individual who has multiple conditions
  - Communicating with multiple health care professionals
  - Feeling that one has to be constantly watching, does not have a choice, or has pressure from others to take on the role
  - Rating tasks as difficult to perform

# Negative Effects on Quality of Life\*

- Added stress and vigilance
- Worry about making a mistake (more for Millennials and Generation X)
- Worry about paying for care (more for Millennials and Generation X)
- Negative effects on employment (except Silent generation)
- Chinese caregivers face more challenges:
  - 2/3 worry about paying for care, making a mistake and worrying about something going wrong
  - Twice as likely to say that performing tasks causes problems in relationships with care recipient

*\* Negative effects are significantly worse with more tasks and with a greater number of conditions*

# Positive Effects on Quality of Life

- Feeling about making an important contribution (greatest for Hispanic/Latino and Black/African American caregivers and for Boomer and Generation X caregivers)
- Feeling closer to the care recipient
- Performing tasks also eases worry
- Gives the caregiver new skills (particularly Hispanic/Latino, Black/African American, and Chinese family caregivers and Generation X and Millennial caregivers)



# Caregiver Strain

- 75% of caregivers experience aspects of strain sometimes or more frequently
- 23% of women and 16% of men stressed trying to balance caring with other responsibilities
- Almost half of M/N caregivers feel down, depressed, or hopeless compared with a third of caregivers who are not performing M/N tasks

Caregiver Strain, % (n = 1,084)

	Nearly Always	Quite Frequently	Sometimes	Rarely	Never
Not enough time for myself	6	12	32	25	25
Stressed between care and other responsibilities	7	13	35	21	23
Strained when around family member	5	8	25	25	36
Uncertain about what to do	6	10	26	24	33

# Avoiding a nursing home

- The more tasks the caregiver performs and the more conditions the care recipient has, the more likely the caregiver recognizes their role in keeping the care recipient at home
- Avoiding a nursing home is associated with:
  - Higher number of M/N tasks
  - Stress of communicating with multiple health care professionals or suppliers
  - Feel they are constantly watching for something to go wrong
  - Being female
  - Motivated by cultural or religious influences to provide care
  - Having a home visit from a health care professional

## **Finding #5 - Many family caregivers are still on their own—health systems should do *more to prepare* these vital members of the team**

- Caregivers are largely on their own in learning how to perform medical/nursing tasks they find difficult to perform, such as managing incontinence and preparing special diets.
- Three out of 5 caregivers whose family members were hospitalized in the past year report that they received instruction on how to perform medical/nursing tasks, but more work needs to be done in identifying family caregivers and giving them timely notification of hospital discharge.

# Translating Research Into Policy:

## The Caregiver Advice, Record and Enable Act

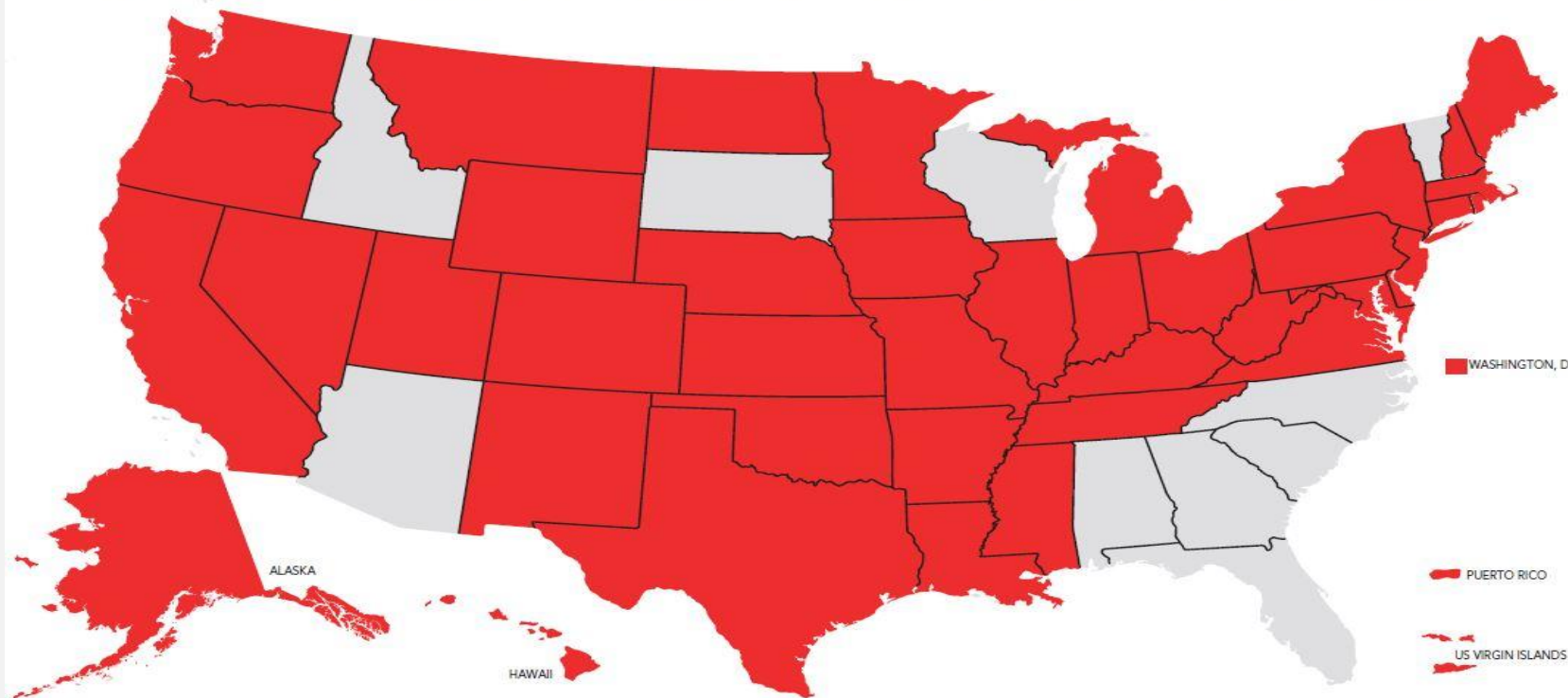
- AARP developed model legislation for the CARE Act
- Under the CARE Act:
  - Hospitals must identify a family caregiver for inpatient admissions and record the family caregiver in the medical record
  - Hospitals must notify the family caregiver of discharge plans for the person in the hospital
  - Family caregivers must be offered training on medical/nursing tasks they may be asked to perform

**Law in 40 states, DC, Puerto Rico and USVI**

# CARE Act

## 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 ones return home.



### CARE Act goes into effect:

Alaska, 1/1/17; Arkansas, 7/22/15; California, 1/1/16; Colorado, 5/8/15; Connecticut, 10/1/15; Delaware, 1/1/17; Hawaii, 7/1/17; Illinois, 1/27/16; Indiana, 1/1/16; Iowa, 7/1/19; Kansas, 7/1/18; Kentucky, 6/29/17; Louisiana, 8/1/16; Maine, 10/15/15; Maryland, 10/1/16; Massachusetts, 11/8/17; Michigan, 7/12/16; Minnesota, 1/1/17; Mississippi, 7/1/15; Missouri, 8/28/18; Montana, 10/1/17; Nebraska, 3/30/16; Nevada, 10/1/15; New Hampshire, 1/1/16; New Jersey, 5/12/15; New Mexico, 6/17/15; New York, 4/23/16; North Dakota, 8/1/19; Ohio, 3/21/17; Oklahoma, 11/5/14; Oregon, 1/1/16; Pennsylvania, 4/20/17; Puerto Rico, 12/31/15; Rhode Island, 3/14/17; Tennessee, 6/6/19; Texas, 5/26/17; Utah, 2/10/16; Virgin Islands, 3/30/16; Virginia, 7/1/15; Washington, 6/9/16; Washington, DC, 7/6/16; West Virginia, 6/8/15; Wyoming, 7/1/16

Updated on 6/6/19

 CARE Act Now Law

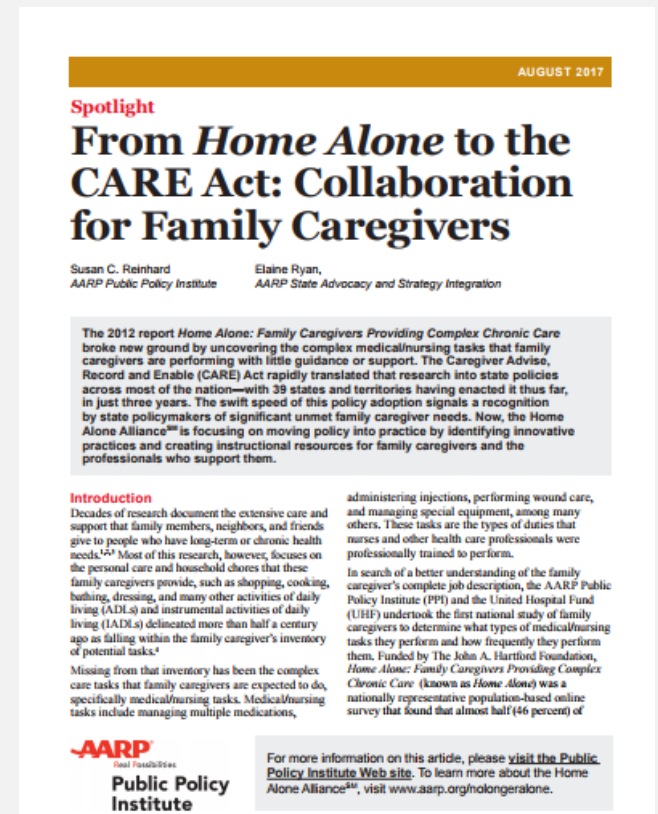
I  Caregivers  Real Possibilities

# National CARE Act Scan Findings

- AARP published an in-depth spotlight on the CARE Act, including initial findings from the National Scan.
- Highlights both passage and implementation strategies from states and hospitals and health systems.
- Find the report online here:  
[www.aarp.org/ppi/info-2017/from-home-alone-to-the-care-act.html](http://www.aarp.org/ppi/info-2017/from-home-alone-to-the-care-act.html)

## Promising Practices

- In 2019, AARP released, The CARE Act Implementation: Progress and Promise  
<https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf> trends from a state scan.





# \$6,954

Average Out of Pocket Expenses for Family Caregivers in 2016

# \$11,923

Average Out of Pocket Expenses for Long-Distance Caregivers in 2016

## Family Caregivers Provide \$470 Billion in Unpaid Care

Source: Valuing the Invaluable 2015 Update: Undeniable Progress, but Bigs Gap Remain, AARP Public Policy Institute

More than three in four family caregivers (78%) are incurring out-of-pocket costs as a result of caregiving

# 78%

# 20%

Family caregivers are spending, on average, nearly 20% of their income on caregiving activities



# **FAMILY CAREGIVING IN WISCONSIN:** A SURVEY OF REGISTERED VOTERS AGE 40 AND OLDER

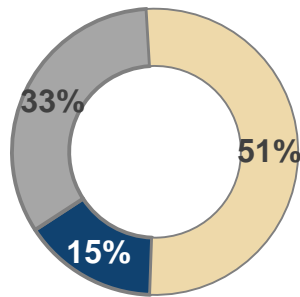
August 2019  
Prepared by Terri Guengerich





# Nearly half of voters 40-plus in Wisconsin have experience as family caregivers.

In our survey, the typical family caregiver in Wisconsin, currently caring for an adult loved one, is a woman (68%), who is married (67%), is 59 years of age, owns her own home (80%), is in good health (81%), and lives in a household with income under \$75,000 (51%).



■ Current Caregiver  
■ Former Caregiver  
■ Never a Caregiver

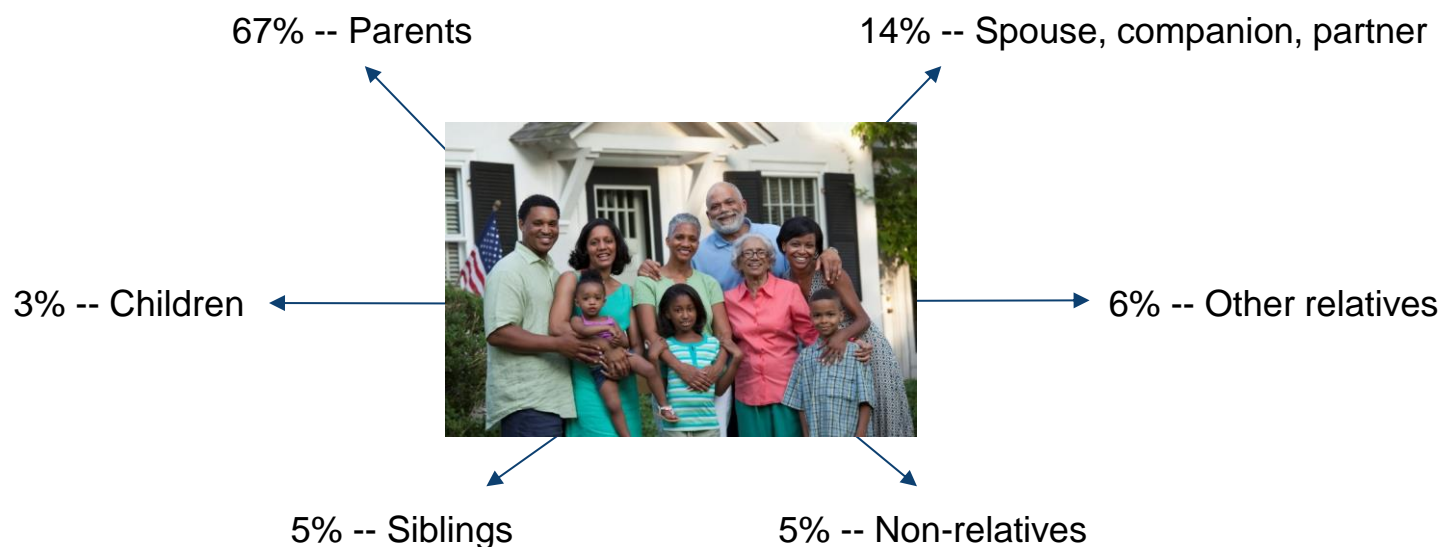
- Typical current caregivers also ....
  - Are likely to be currently working (51%), but more had worked at some point while caregiving (70%)
  - Are not likely to have children living at home (65%), but many do (32%)
  - Cares for a parent who is 80 years of age
  - Are likely to have a college degree (62%)
  - Does not live with their loved one (63%), but lives within 20 minutes of him/her (70%).



Q1. A family caregiver is someone who provides UNPAID care for an adult loved one who is ill, frail, elderly, or has a physical, mental, or emotional disability. This unpaid care may include assisting with personal needs like bathing and dressing, household chores, meals, shopping, transportation, or managing finances or medical care. Are you currently a family caregiver providing UNPAID care to an adult loved one?  
Q14. Have you ever been a family caregiver who provided UNPAID care to an adult loved one? Donut Base: All Respondents Chart Base: Current Caregivers (other surveys questions are listed in the Appendix)

# Most caregivers are caring for or have cared for their parents.

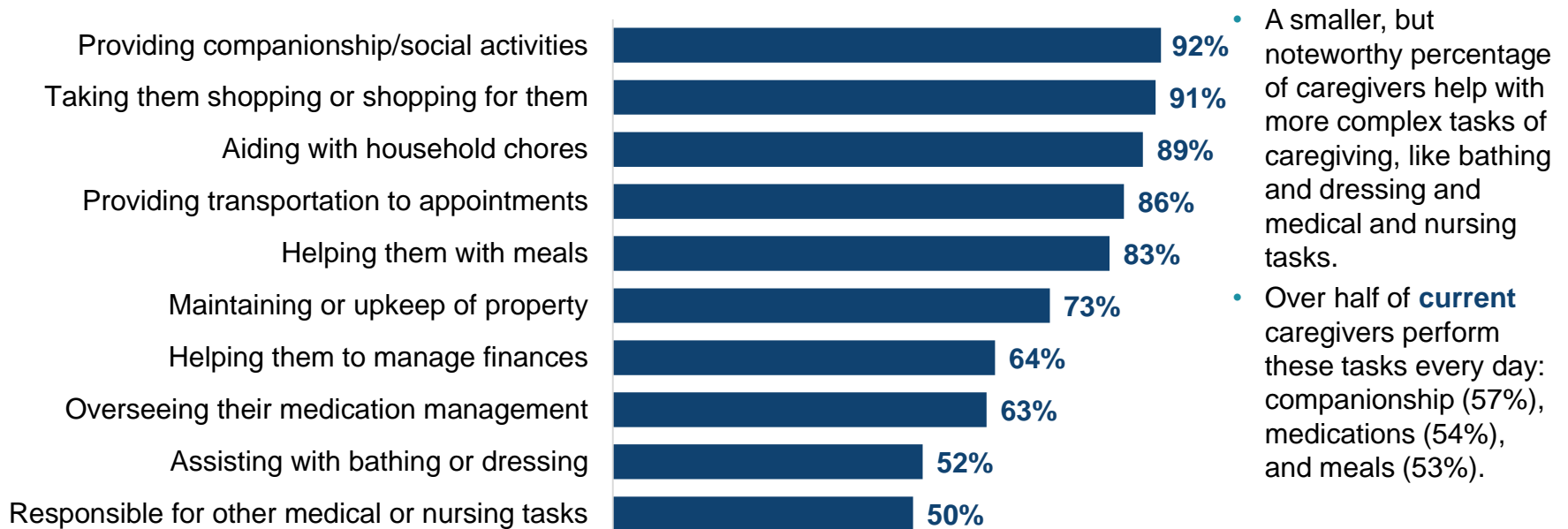
Two in three current and former caregivers in Wisconsin are providing or have provided care to their parents – most likely their mother (41%). One in seven is caring for or has cared for their spouse or significant other; and fewer are caring for or have cared for other relatives such as grandparents, uncles, or aunts. Very few care for or have cared for children who are 18 and older, siblings, or non-relatives such as neighbors or friends.



Q3. Who are you caring for? Q16. Who did you care for? Base: Current and former caregivers

# Family caregivers help their loved ones with many activities of daily living.

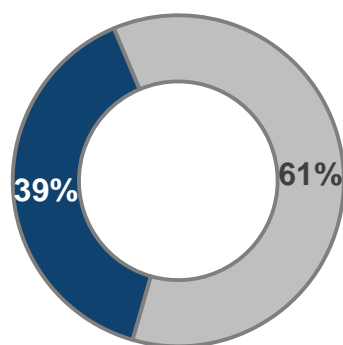
Over nine in ten family caregivers surveyed (both current and former caregivers) help with shopping and provide emotional support to their loved ones through companionship or social activities. About nine in ten help their loved one with chores. Over eight in ten help with meals and transportation. About three in four maintain property, and about two in three oversee medications or manage finances.



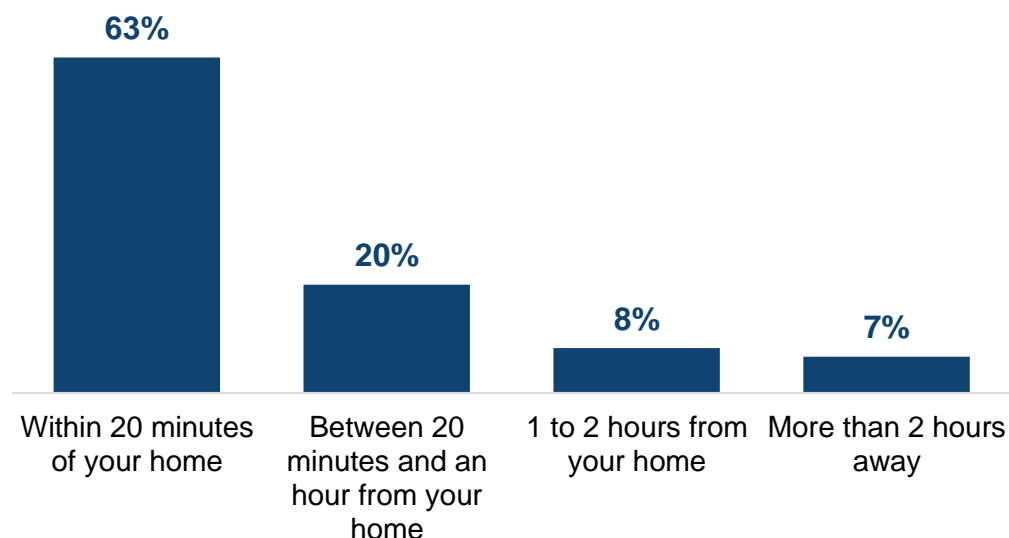
Q4. Still thinking about the person you are providing care to the most, which of the following activities are you providing? Are you ...? Q17. Thinking about the person you most recently provided care to, which of the following activities did you provide? Did you ...? Q5. How often do you ..., is it? Chart Base: Current and Former Caregivers 2<sup>nd</sup> Bullet: Current Caregivers

## Most caregivers do not live with their loved one.

Two in five family caregivers 40-plus say the person they are caring for or had cared for lived in their household; while most care recipients did not. However, of those caregivers whose loved one didn't live with them, over six in ten didn't live far away – at most 20 minutes. Over one in seven caregivers provided care from a distance – living at least an hour from their loved one.



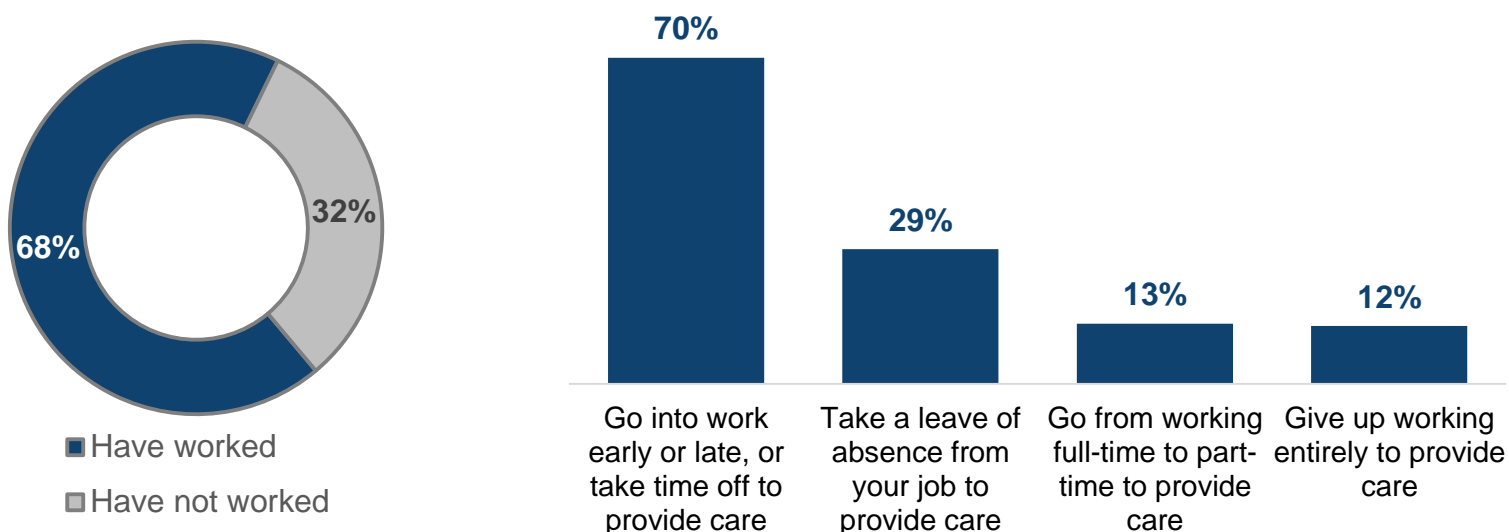
■ Live with loved one



Q6, Q18.

## Most caregivers have worked while providing care.

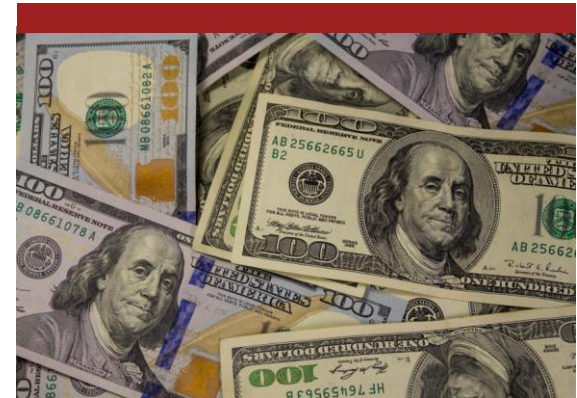
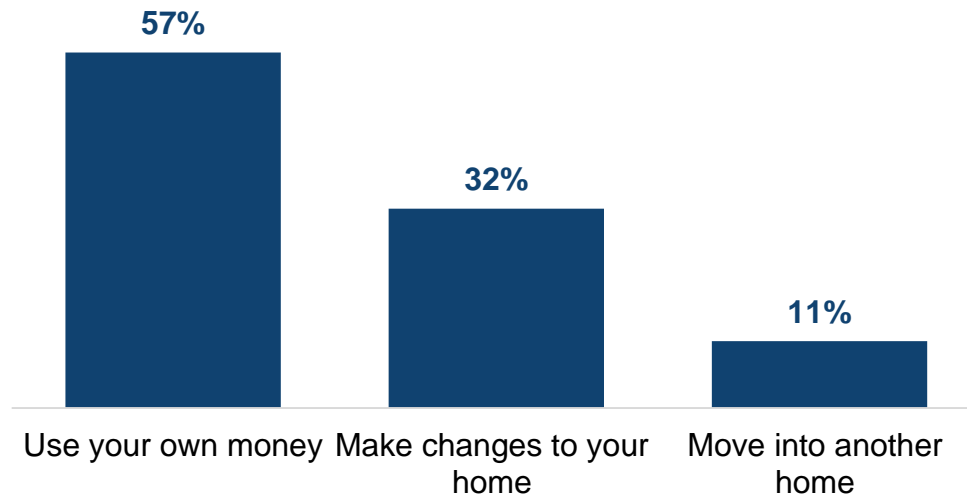
Two in three family caregivers 40-plus held a job while providing care to their loved ones. And many of these caregivers needed to change how they worked as well. Seven in ten working caregivers adjusted their work schedules, either by going into work early or late, or taking time off to provide care – most needed to do so weekly (20%) or monthly (47%). Three in ten took a leave of absence to provide care. And just over one in ten reduced their work hours to provide care or stopped working entirely.



Q6. Q18. Have you ever been employed either full- or part-time while providing care to your adult loved one? Q7. Now thinking again about the adult loved one you are currently providing care to, did you ever have to ...? Q19. Now thinking again about the adult loved one you have most recently provided care to, did you ever have to ...? Q8. Q20. You mentioned that you had to go into work early or late, or take time off to provide care to an adult loved one. How often would you say you had to take time away from work or adjust your work schedule to provide care for someone. Would you say ...? Donut Base: Current and Former Caregivers Chart Base: Current and Former Working Caregivers

# Caregivers spend money to provide care and change their homes.

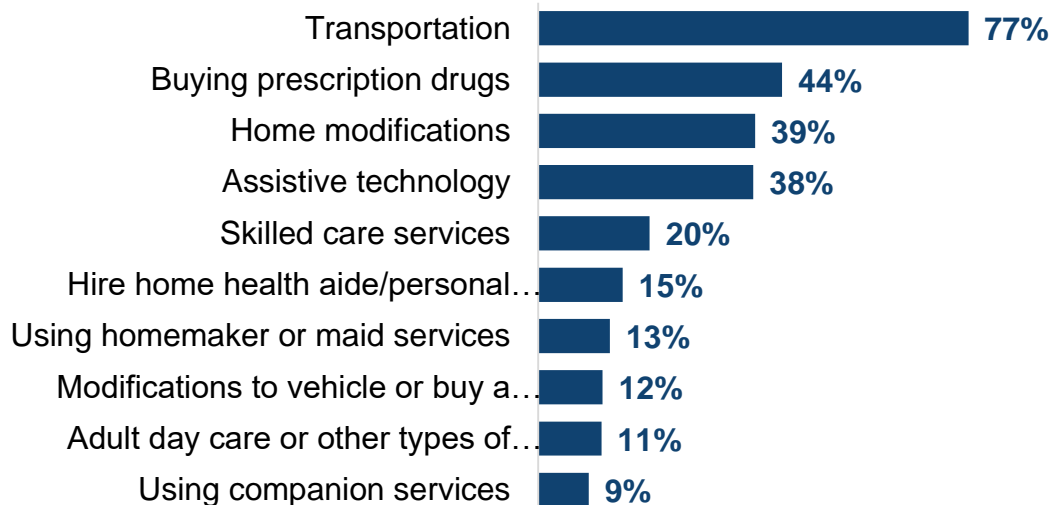
Nearly six in ten current and former caregivers 40-plus in Wisconsin have used their own money to provide care to their loved ones. About one in three has modified their own homes, and one in ten has moved into another home.



*Q9. Now thinking again about the adult loved one you are currently providing care to, did you ever have to ...? Q21. Now thinking again about the adult loved one you have most recently provided care to, while providing this care did you ever have to ...? Chart Base: Current and Former Caregivers*

# Most caregivers spend money transporting their loved ones.

Of those 57% of caregivers who have spent their own money to provide care to their loved ones, three in four caregivers have spent money to transport their loved ones. About four in ten spent money on prescription drugs, modifying their homes or their loved ones' home, or on assistive technology. Fewer have spent money on services that could help to care for their loved ones.

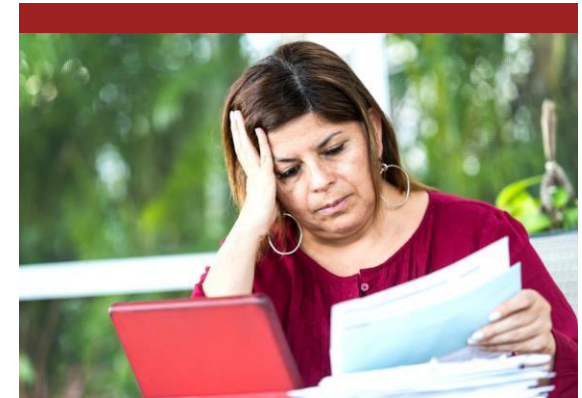


Q10. As a caregiver, have you ever spent your own money to help care for your loved one for any of the following? Q22. As a caregiver, did you ever spend your own money to help care for your loved one for any of the following? Chart Base: Current and Former Caregivers Who Have Spent Money Providing Care

# Most caregivers experience some form of stress while providing care.

Over eight in ten family caregivers (84%) have experienced at least one of the stressors asked about in this survey. Two in three caregivers report feeling stressed out emotionally due to their caregiving responsibilities; and two in three working caregivers are stressed in trying to balance their job and family responsibilities.

	Current & Former Caregivers
Feel stressed emotionally	67%
Feel stressed in trying to balance job and family*	68%
Find it difficult to get enough rest	52%
Find it difficult to take care of household	47%
Find it difficult to exercise regularly	42%
Find it difficult to maintain a healthy diet	32%
Experience problems with health	27%
Feel strained financially	25%
Find it difficult to find time to visit doctor	20%



Q11. As a caregiver do you ever ...? Q23. As a caregiver did you ever ...? Chart Base: Current and Former Caregivers \*Asked of working caregivers



# Many registered voters 40-plus in Wisconsin say they are likely to be a caregiver in the future.

Likelihood of providing care in the future does vary by caregiver status. Not surprisingly, over three in four current caregivers say they are extremely or very likely to provide care in the future. Four in ten former caregivers and a fifth of those who have never provided care, say they are extremely or very likely to be a caregiver in the future. Younger respondents (40-64) are more likely to say they will be providing care in the future (44%) than respondents 65-plus (25%).

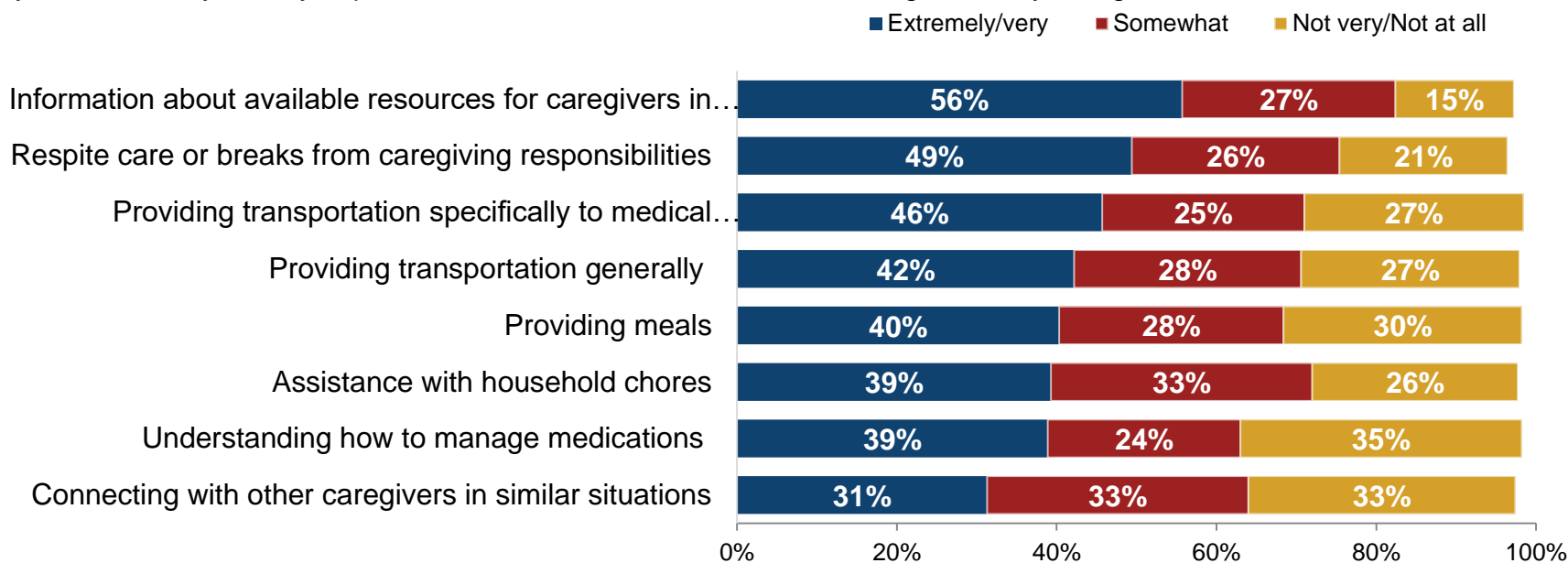
	Current Caregivers	Former Caregivers	Never a Caregiver	All Respondents
Extremely/very likely	78%	41%	22%	37%
Somewhat likely	11%	22%	28%	23%
Not very/Not at all likely	11%	34%	47%	37%



Q13. Q25. Q26. How likely do you think it is that you will provide any caregiving or assistance on an unpaid basis for an adult loved one in the future? Is it ...?

## The most helpful caregiver support is information about caregiving resources in community.

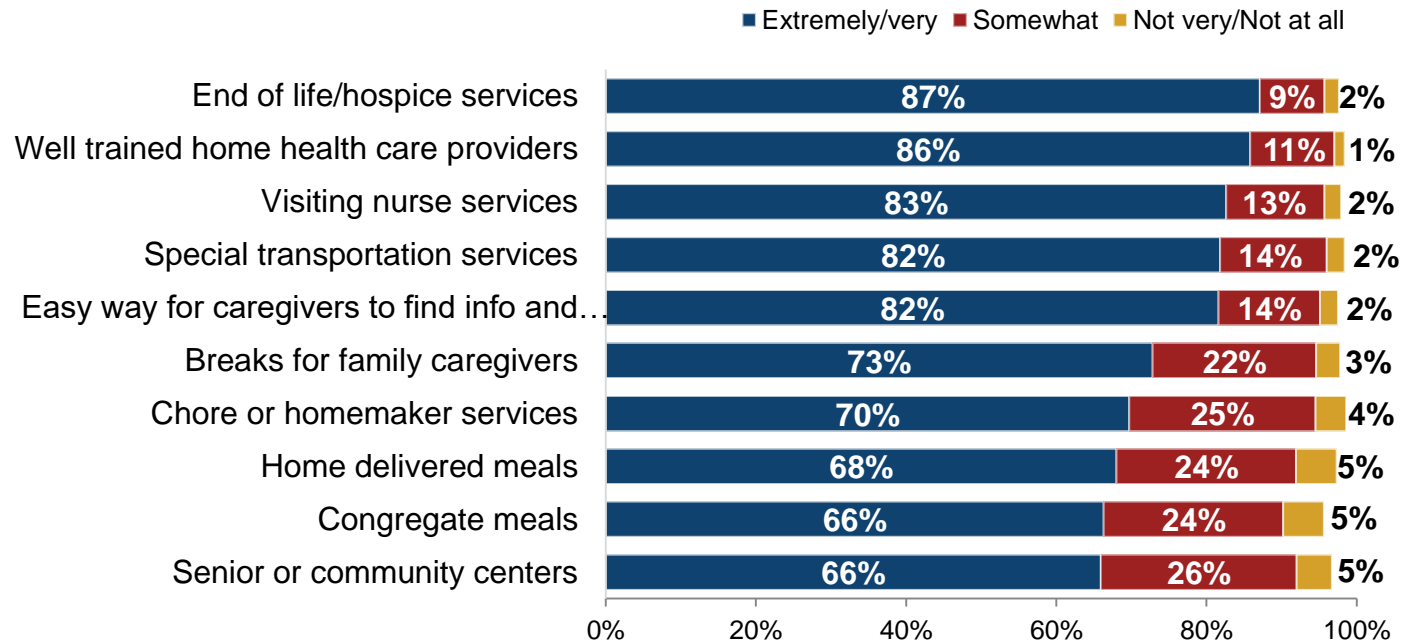
Nearly half of voters in Wisconsin would also find respite care helpful. Over four in ten would find assistance with transportation to medical appointments and in general helpful. About four in ten would also find assistance with medication management, household chores, and meals helpful. In addition to these helpful supports, nearly three in four voters (73%) say it is extremely or very important to have more resources and training for family caregivers.



Q27. In your opinion, as a current caregiver, how helpful would the following types of caregiving support be to you? In your opinion, as a former caregiver, how helpful would the following types of caregiving support be to you? In your opinion, as someone who may provide care in the future, how helpful would the following types of caregiving support be to you? Q28. Family caregivers help older residents in Wisconsin live independently by performing services like bathing and dressing as well as managing medication and paying bills. How important do you think it is to have more resources and training for family caregivers? Chart Base: All Respondents

## Hospice services and well trained home health care providers top the list as the most important services to have in Wisconsin communities.

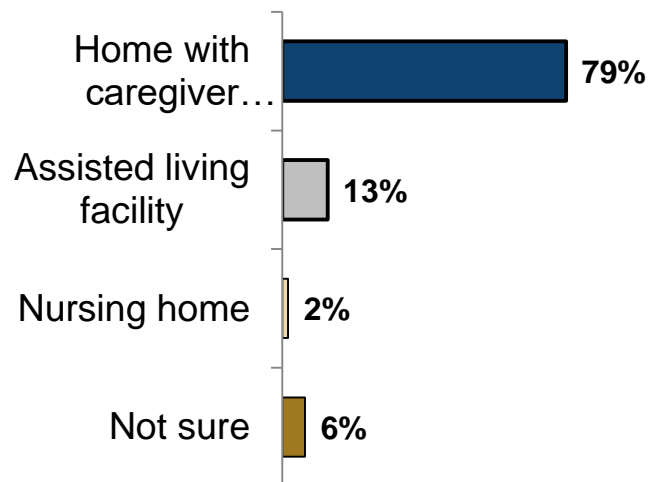
At least eight in ten voters also say that visiting nurse services, special transportation services, and an easy to find caregiving resources are extremely or very important services to have in their communities.



Q47. Now I'm going to ask you about some specific community services. Please tell me how important you think it is to have the following services available in your community to help older adults live independently. How important is having XXX in your community? Is it ...? Chart Base: All Respondents

# Most voters prefer being cared for at home if they need help.

Eight in ten voters say that if they or a family member needed help, they would prefer to receive that help at home with caregiver assistance. Over one in ten would prefer to receive help in an assisted living facility, and only two in a hundred would prefer a nursing home.



- Nine in ten caregivers (91%) also say it is extremely or very important to be able to provide care so their loved ones could keep living independently at home.



Q35. If you or a loved one needed help when the basic tasks of life become more difficult due to aging or illness, where would you prefer to receive that care or help for yourself or a loved one? Q12. How important is it to you to be able to provide care for your loved one so that they can keep living independently in their own home? Q24. How important was it to you to be able to provide care for your loved one so that they could keep living independently in their own home? Chart Base: All Respondents Bullet Base: Current and Former Caregivers

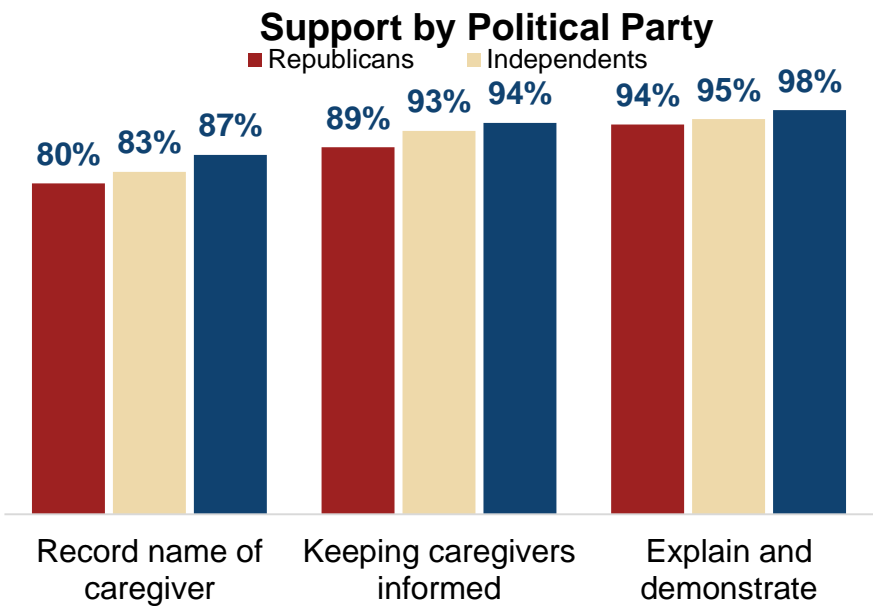
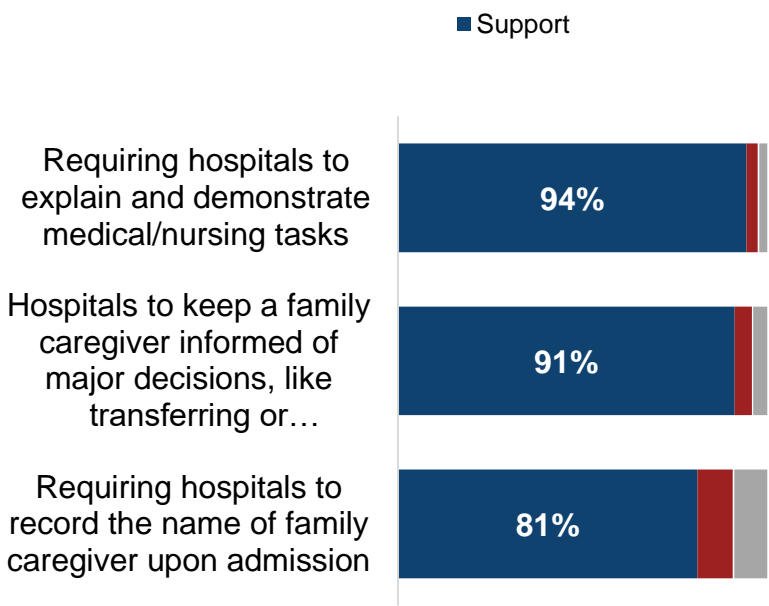


## THE CARE ACT



# There is overwhelming support by Wisconsin voters 40-plus for the CARE Act.

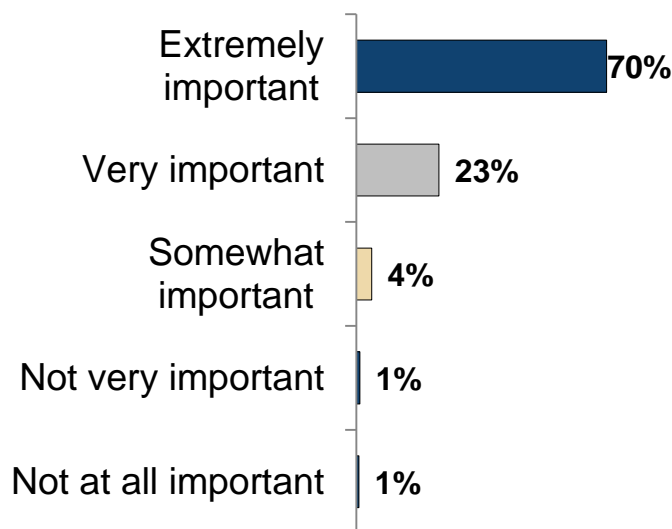
Over eight in ten voters support these three components of the CARE Act that help family caregivers when their loved ones go into the hospital and as they transition home. Support remains high for the CARE Act across political parties.



Q26. Now I'm going to ask if you support or oppose some proposals that would provide additional help for family caregivers. Do you support or oppose ...? Q27. Is that strongly or somewhat? D11. Do you consider yourself to be a ...? Chart Base: All Respondents

## Voters 40-plus believe that hospital discharge instructions are important.

Over nine in ten voters in Wisconsin 40-plus (93%) say it is extremely or very important to receive medical instructions for tasks to be provided at home when a loved one is discharged from the hospital.



- 76% of current and former caregivers say their loved ones did require admission to a hospital
  - Of these caregivers, six in ten (62%) say they were provided with instructions or a live demonstration of medical tasks they would need to perform at home. However, **one in three (34%) were not** provided such instruction or demonstration, and 4% were not sure.

Q28. Thinking about right now – today – if you had to care for a family member after their discharge from a hospital, how important would it be for you to get instruction on any medical tasks you may need to provide for your loved one at home? Is it ...? Q29. Thinking about right now – today – if your family member or loved one was being discharged from a hospital, how important would it be for you to get instruction on any medical tasks you may need to provide for your loved one at home? Is it ...? Q30. At any time while you have been providing care, did your family member or loved one require admission to a hospital? Q31. Upon their discharge from the hospital, were you provided with instruction or live demonstration of any medical tasks that you may need to perform for your family member or loved one at home? Chart Base: All Respondents

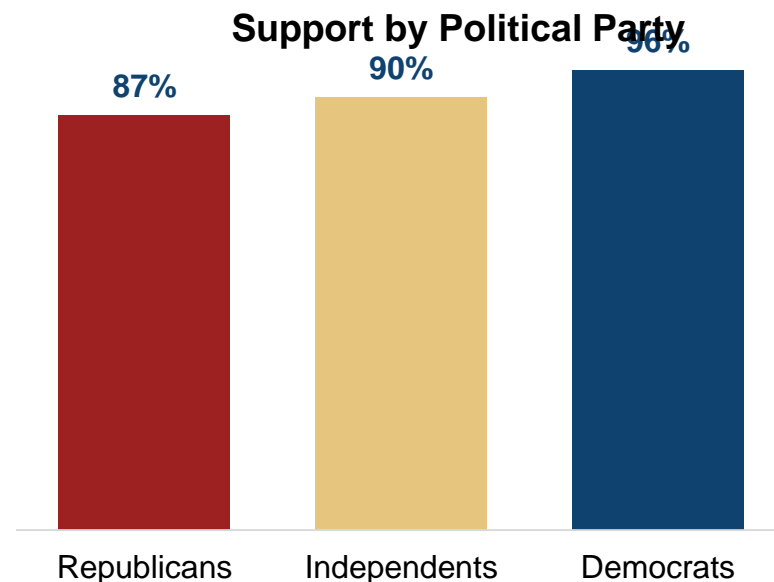
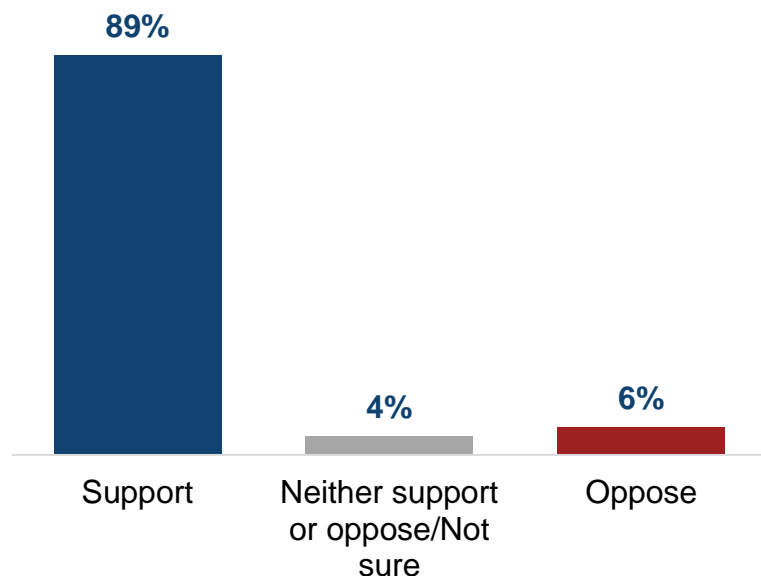


## TAX CREDIT



## There is overwhelming support by Wisconsin voters 40-plus for a state income tax credit to family caregivers who incur expenses.

Nine in ten voters support a state income tax credit for family caregivers who incur expenses while providing care to a family member living in Wisconsin. Support remains high across political parties.



Q31. Do you support or oppose providing a limited state income tax credit to family caregivers who incur expenses for the care and support of a family member living in Wisconsin? Q32. Is that strongly or somewhat? Chart Base: All Respondents

# AARP State Family Caregiving Advocacy Agenda

## Caregiver Support and Education

- CARE Act
- CARE Act Implementation

## Workplace Flexibility

- Paid and Unpaid Leave
- FMLA expansion
- WORC, ELECT
- Paid Sick Leave
- Respite Care
- RELIEF

## Expanded Options for Care

- Telehealth
- APRN Scope of Practice
- Nurse Delegation
- Registries

## Home and Community Based Services (HCBS)

- MLTSS
- Quality across settings
- Antipsychotics
- Improve/protect program/funding
- Navigation

## Financial and Legal Solutions

- Guardianship
- Caregiver Tax Credit
- WINGS
- Uniform Power of Attorney Act

# Additional Resources

<b>Caregiving in the U.S. 2015</b>	<a href="https://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015.html">https://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015.html</a>
<b>Valuing the Invaluable 2015</b>	<a href="https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html">https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html</a>
<b>Valuing the Invaluable 2019</b>	<a href="https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html">https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html</a>
<b>Home Alone: Family Caregivers Performing Complex Care</b>	<a href="https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf">https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf</a>
<b>Home Alone Alliance</b>	<a href="http://www.aarp.org/nolongeralone">http://www.aarp.org/nolongeralone</a>
<b>LTSS State Scorecard</b>	<a href="http://longtermscorecard.org">http://longtermscorecard.org</a>

# Additional Resources

<b>Millennial Family Caregivers</b>	<a href="https://www.aarp.org/ppi/info-2018/millennial-family-caregiving.html">https://www.aarp.org/ppi/info-2018/millennial-family-caregiving.html</a>
<b>Male Family Caregivers</b>	<a href="https://www.aarp.org/content/dam/aarp/ppi/2017-01/Breaking-Stereotypes-Spotlight-on-Male-Family-Caregivers.pdf">https://www.aarp.org/content/dam/aarp/ppi/2017-01/Breaking-Stereotypes-Spotlight-on-Male-Family-Caregivers.pdf</a>
<b>Paid Family Leave</b>	<a href="https://www.aarp.org/ppi/info-2018/breaking-new-ground-supporting-employed-family-caregivers-with-workplace-leave-policies.html">https://www.aarp.org/ppi/info-2018/breaking-new-ground-supporting-employed-family-caregivers-with-workplace-leave-policies.html</a>
<b>Prepare to Care</b>	<a href="http://www.aarp.org/preparetocare">http://www.aarp.org/preparetocare</a>
<b>Military Caregiving Guide</b>	<a href="https://www.aarp.org/content/dam/aarp/caregiving/2019/05/military-caregiving-guide-aarp.pdf">https://www.aarp.org/content/dam/aarp/caregiving/2019/05/military-caregiving-guide-aarp.pdf</a>
<b>The Livability Index</b>	<a href="https://livabilityindex.aarp.org">https://livabilityindex.aarp.org</a>
<b>Caregiving Out of Pocket Costs</b>	<a href="https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/family-caregiving-costs-fact-sheet.doi.10.26419%252Fres.00138.002.pdf">https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/family-caregiving-costs-fact-sheet.doi.10.26419%252Fres.00138.002.pdf</a>
<b>The CARE Act Implementation 2019</b>	<a href="https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf">https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf</a>

# **THANK YOU!**

# **QUESTIONS?**



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