

A vibrant rainbow arches across a bright blue sky filled with soft, white, wispy clouds. The rainbow's colors are clearly visible, transitioning from red on the left to violet on the right. The overall scene is bright and uplifting.

# Caregiving

Both Sides Now:  
You Are the Rainbow in  
Someone's Cloud

# Overview

- Who is a Caregiver
- The scope of Caregiving in America/Hawaii
- Joys of Caregiving
- Caregiver Burden and Stress/Burnout
- Care for the Caregiver
- Resources



# Overview

- Potential stresses and risks of stress
- Potential joys and benefits of joy
- Techniques to reduce stress



# Rosalynn Carter Institute for Caregivers

- “There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”
- Former First Lady of the United States
- [Founder of the Rosalynn Carter Institute for Caregivers](#)



# CAREGIVING in the U.S. 2020

The number of Americans providing unpaid care has increased over the last five years.\*

43.5 million  
2015  53 million  
2020



18%  
2015  21%  
2020

NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.\*\*

More Americans are caring for more than one person.



18%  
2015  24%  
2020

More family caregivers have difficulty coordinating care.

19%  
2015  26%  
2020



More Americans caring for someone with Alzheimer's disease or dementia.



22%  
2015  26%  
2020

More family caregivers report their own health is fair to poor.

17%  
2015  21%  
2020

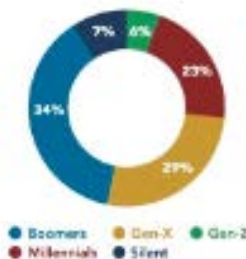


23% OF AMERICANS SAY CAREGIVING HAS MADE THEIR HEALTH WORSE.

Who are today's family caregivers?

  
39%  
MEN

  
61%  
WOMEN



45%  
HAVE HAD AT LEAST ONE FINANCIAL IMPACT

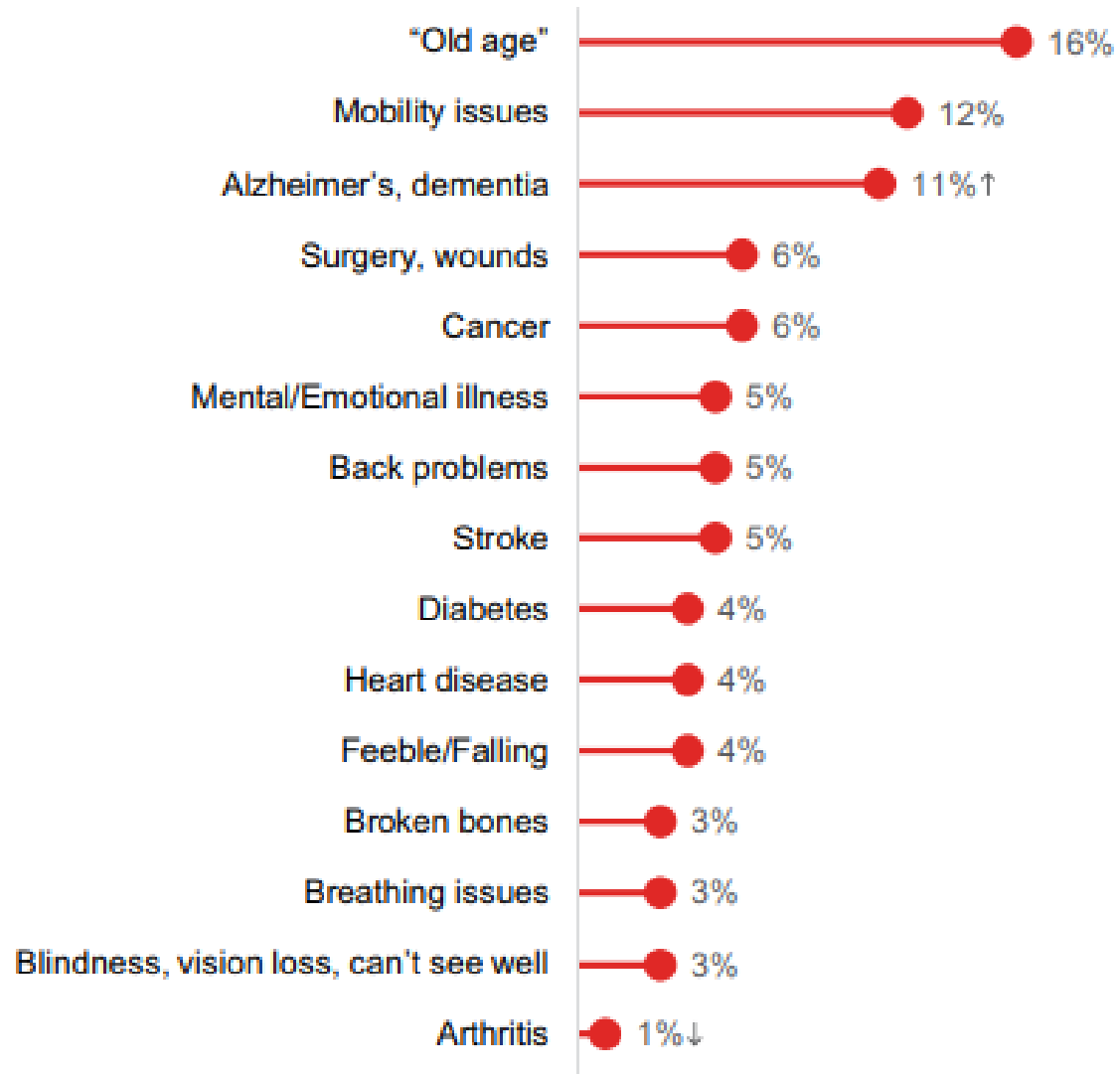
  
61%  
WORK

National Alliance for Caregiving and AARP

# Caregiver Burden

- A [study last year by the Rosalynn Carter Institute for Caregivers](#) found that one in five full-time workers cares for a family member with a serious illness or disability
- Nearly 20 percent of them said they had to quit their job
- 40 percent said they had to go to part-time work



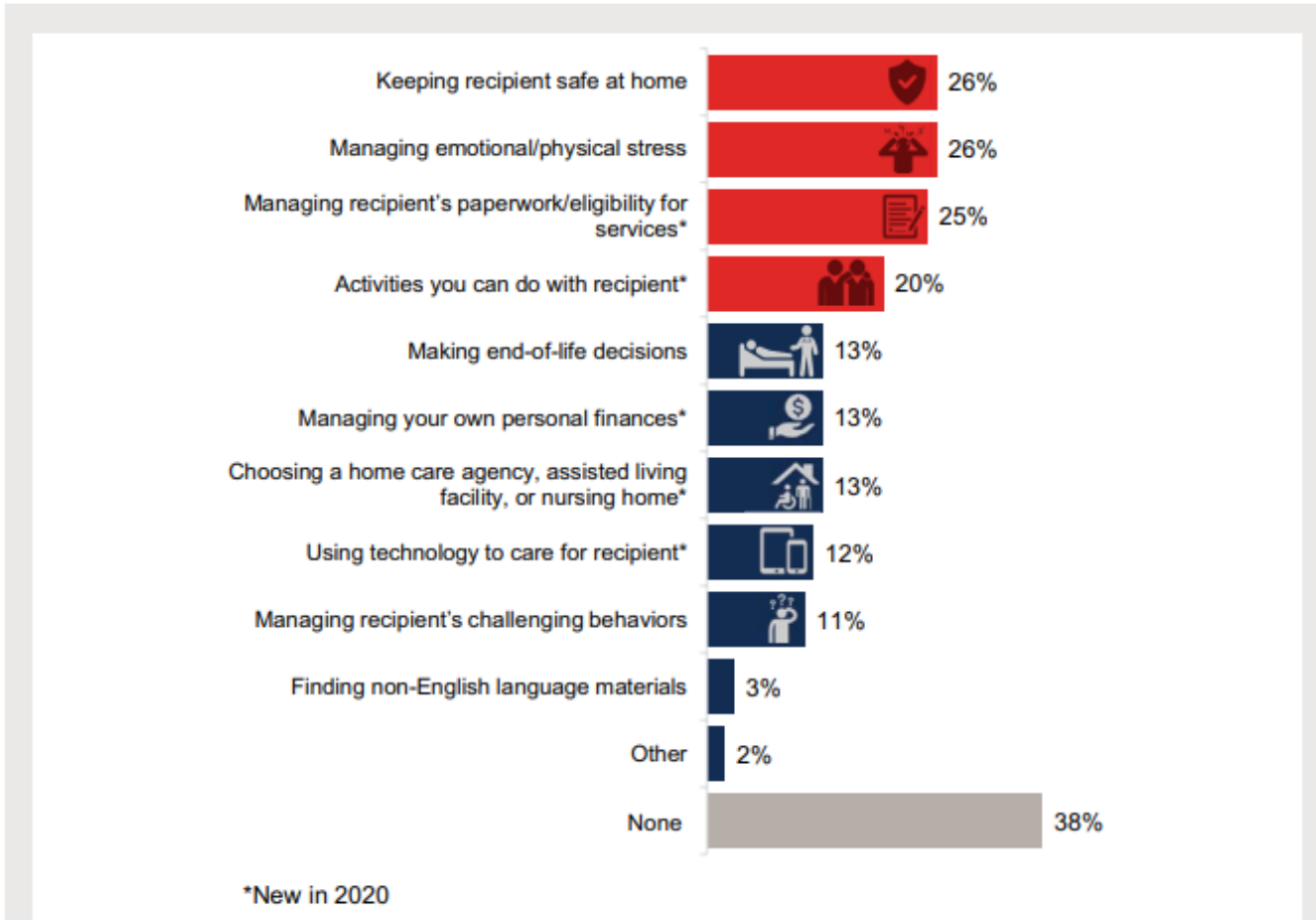


Q18. What is/was the main problem or illness your [relation] has/had, for which they need/needed your care?

**2020 Base: Caregivers of Recipient Age 18+ (n= 1,392)**

# Caregiver Needs and Support Gaps

Figure 74. Caregiver Training and Information Needs

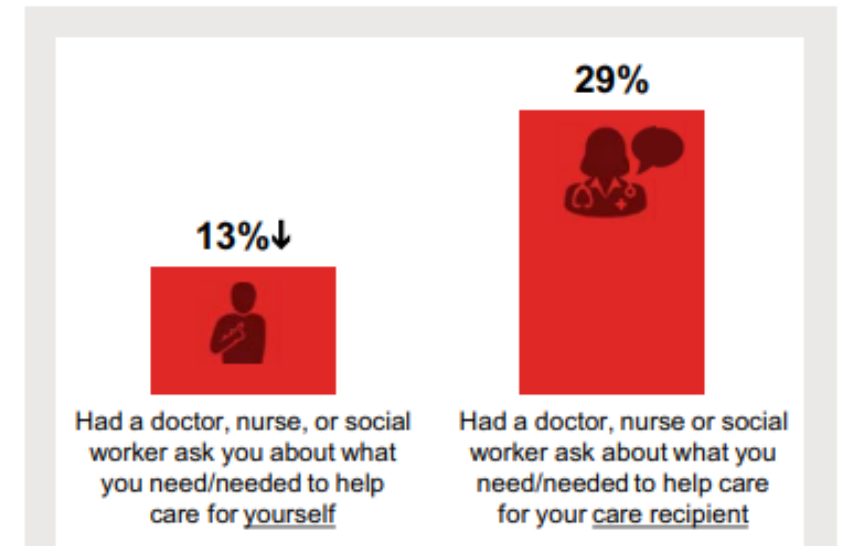


Q48. Which of the following topics do you feel you need/needed more help or information? Select all that apply.

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.

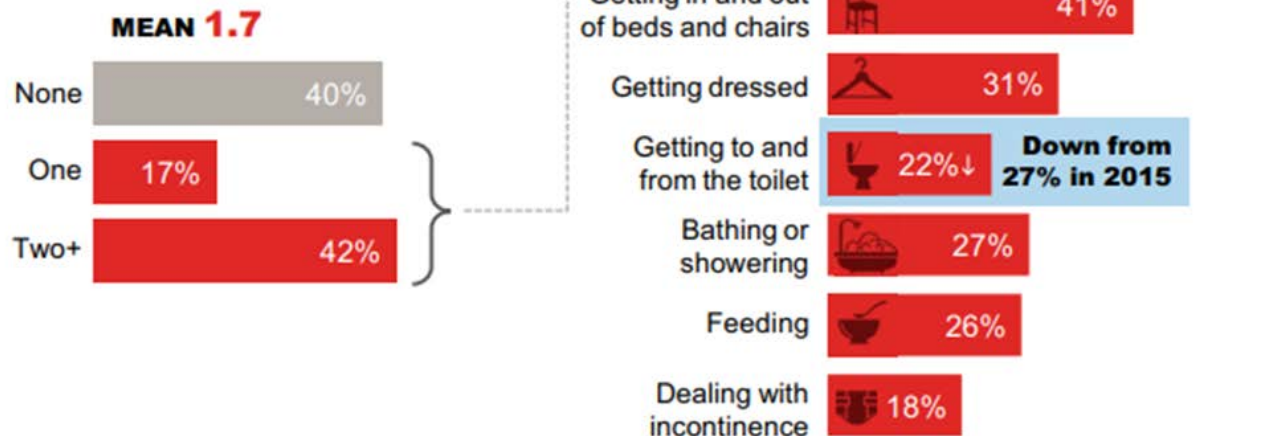
Figure 76. Conversations with Health Care Providers



Q45. In your experience as a caregiver, have you ever ...

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

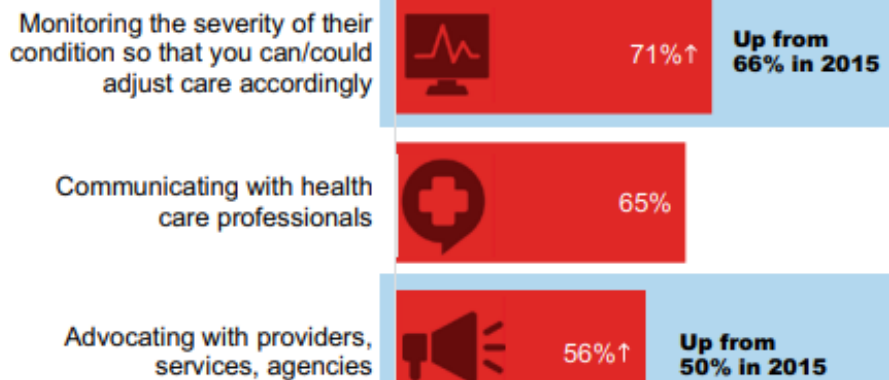




Q22. Which of these do/did you help your [relation] with?

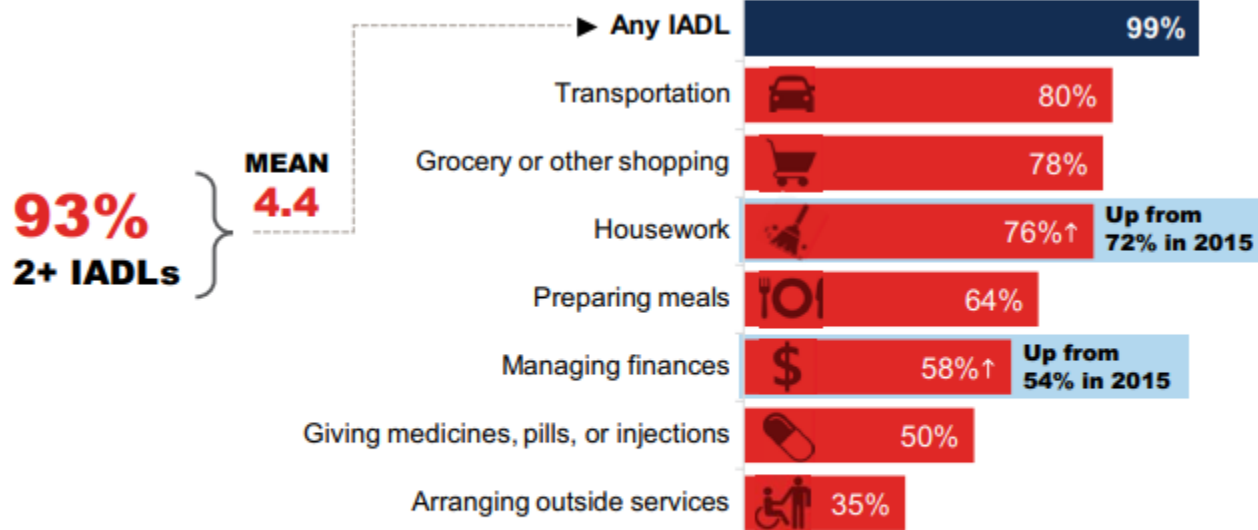
2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.



Q23\_1. And do/did you provide help to your [relation] by...?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

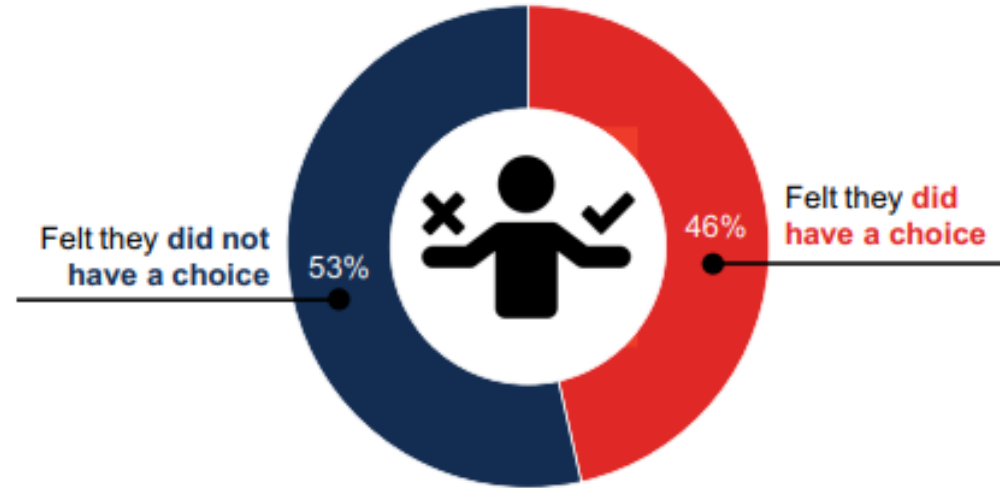


Q23. Do/Did you provide help to your [relation] with...?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.

# Loss of Control



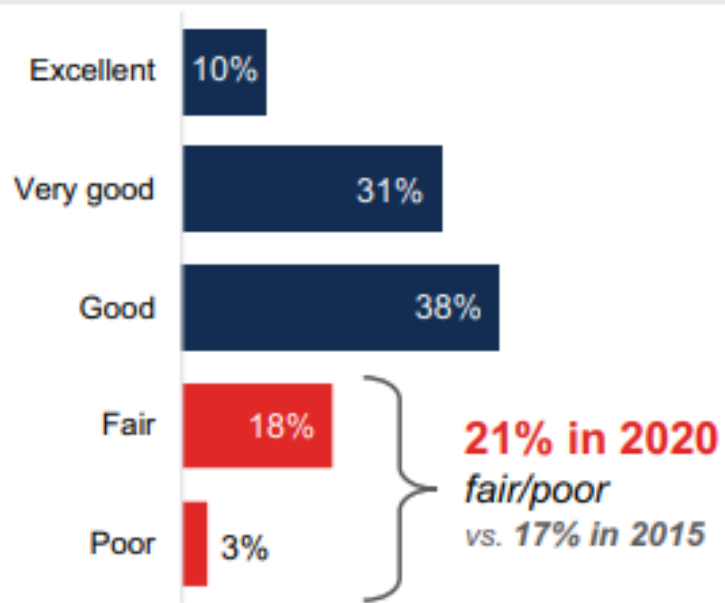
Q39. Do you feel you had a choice in taking on this responsibility for caring for your [relation]?

**2020 Base: Caregivers of Recipient Age 18+ (n=1,392)**

*Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

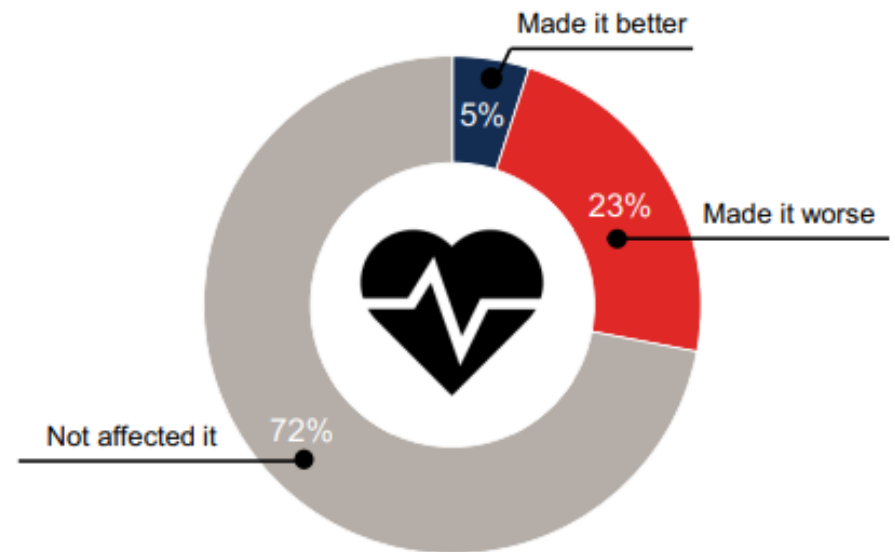


# Feeling Stress



D1. How would you describe your own health? / When you were last caregiving, was your health ...?

**2020 Base: Caregivers of Recipient Age 18+ (n=1,392)**



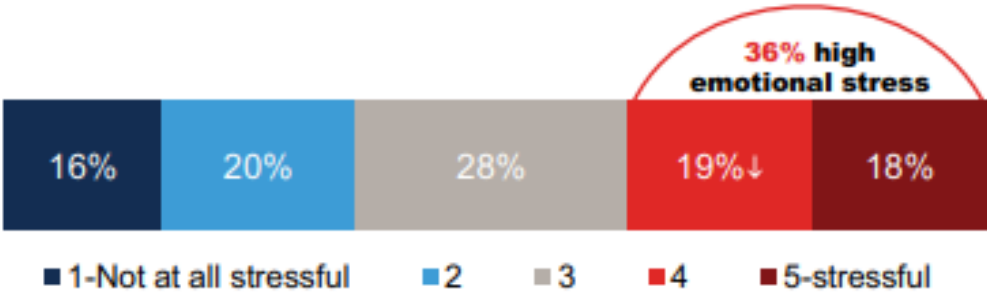
D2. How would you say taking care of your [relation] has affected your health?

**2020 Base: Caregivers of Recipient Age 18+ (n=1,392)**

# Emotional Stress



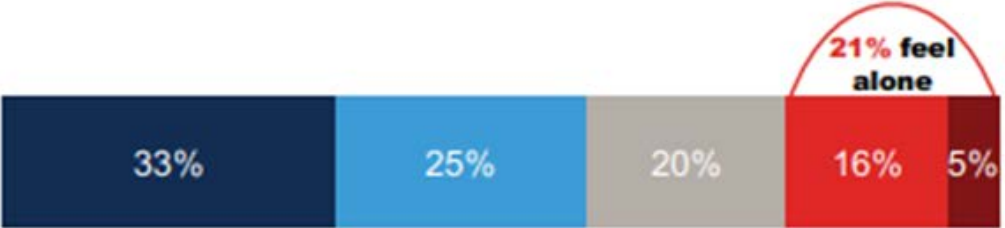
**MEAN 3.0**



Q36. How emotionally stressful would you say that caring for your [relation] is/was for you?

**2020 Base: Caregivers of Recipient Age 18+ (n=1,392)**

*Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*

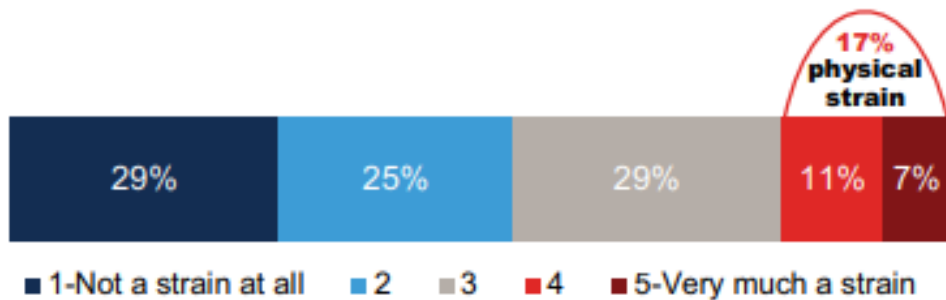


■ 1-Strongly disagree ■ 2-Disagree ■ 3-Neither ■ 4-Agree ■ 5-Strongly agree

M5c. How much do you agree or disagree with each statement below about being a caregiver for your [relation]? "I feel/felt alone"

# Physical Strain

**MEAN 2.4**



Q35. How much of a physical strain would you say that caring for your [relation] is/was for you?

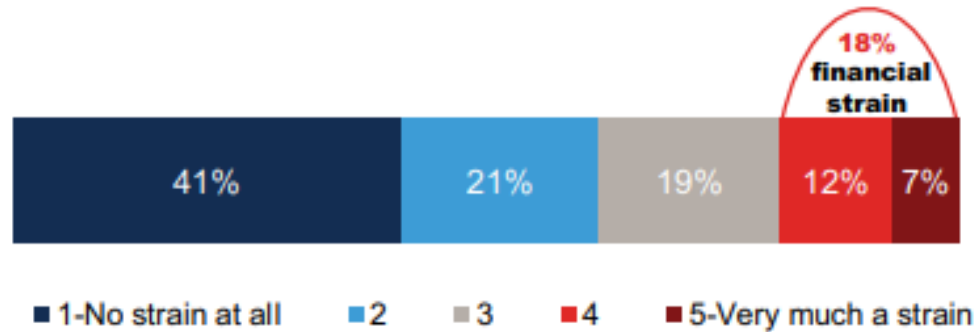
**2020 Base: Caregivers of Recipient Age 18+ (n=1,392)**

*Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*



# Financial Strain

**MEAN 2.2**



Q37. How much of a financial strain would you say that caring for your [relation] is/was for you?

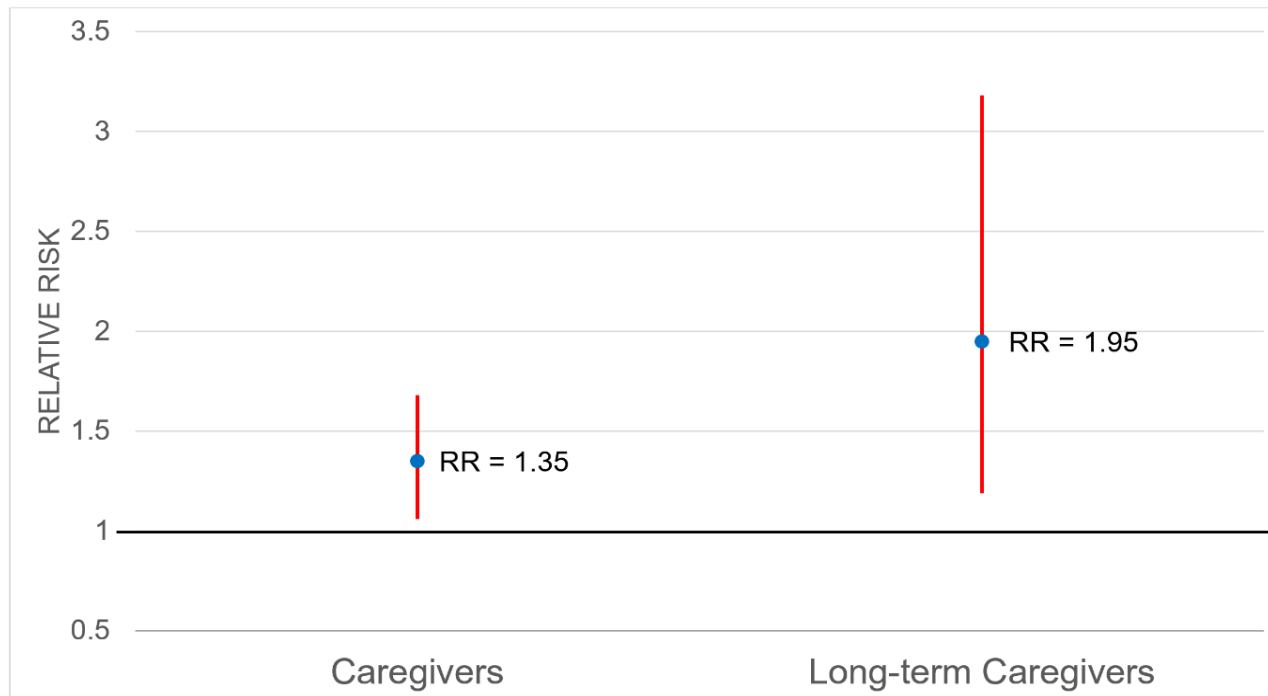
**2020 Base: Caregivers of Recipient Age 18+ (n= 1,392)**

*Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.*



# Dangers of Stress

Relative Risks for Incident Heart Disease or Stroke



HERS Caregiver Study



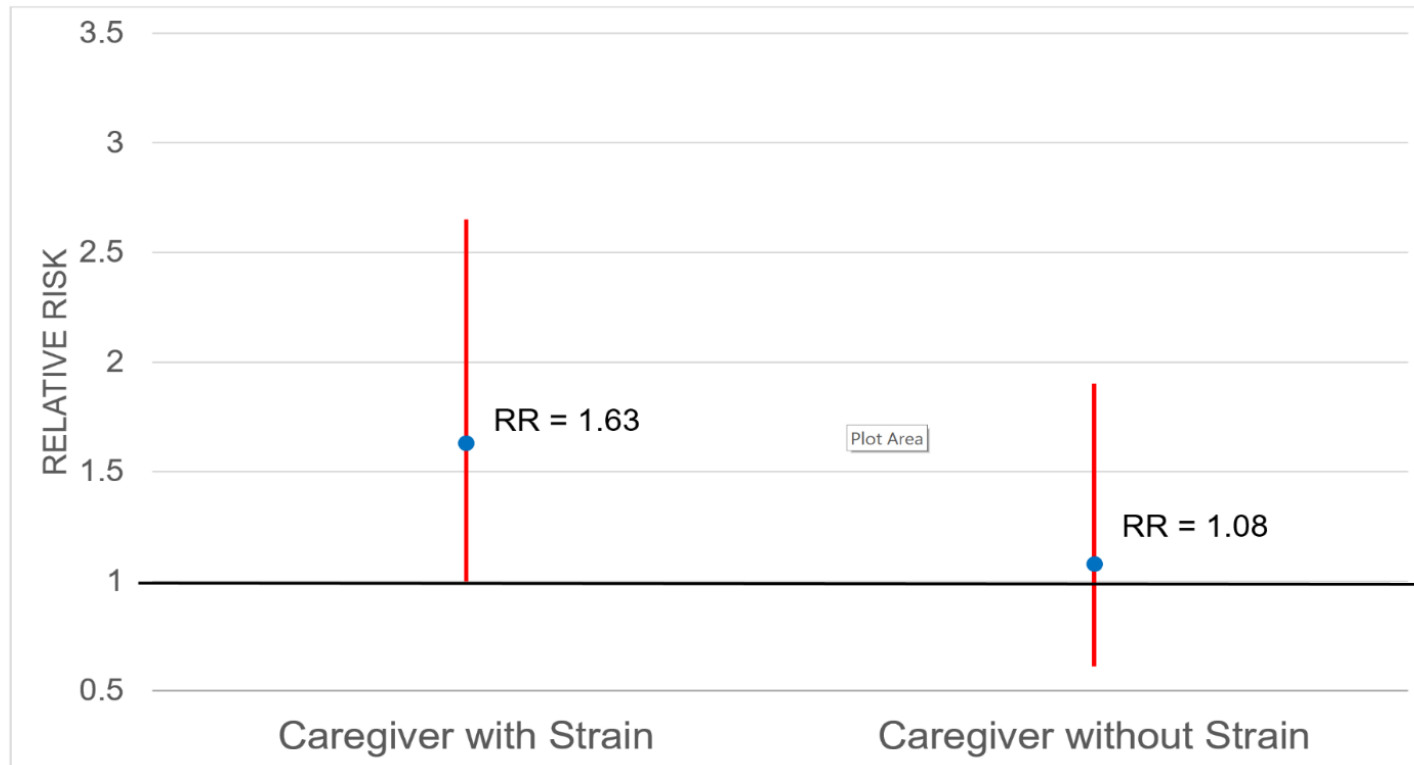
# Dangers of Stress





# Dangers of Stress

Relative Risks for 4-Year All-Cause Mortality



Caregiver Health Effects Study (CHS)



# Screening for Caregiver Burden

## Zarit Caregiver Burden Assessment (Screen, 4-items)

Name: \_\_\_\_\_

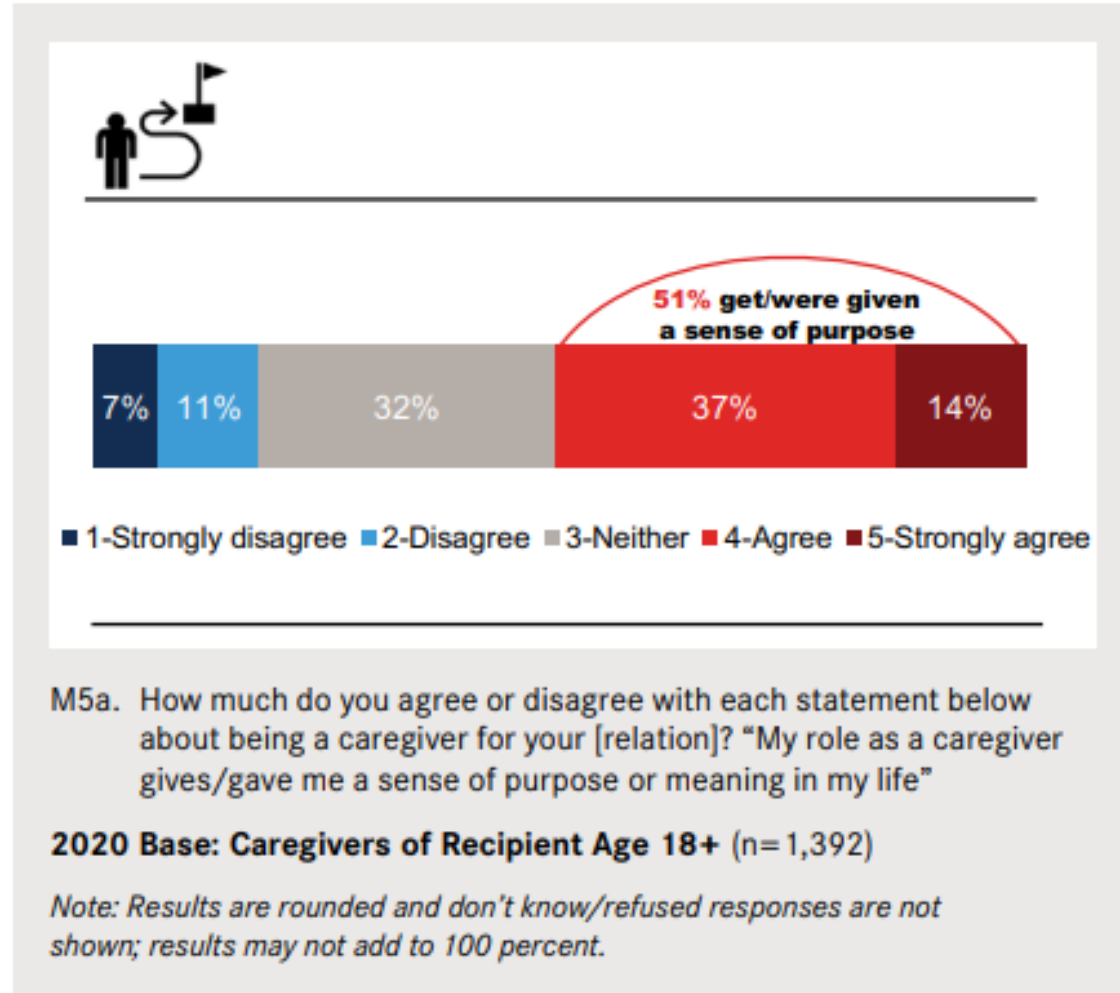
Date: \_\_\_\_\_

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1) Do you feel that because of your relative that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities (work, home)?	0	1	2	3	4
3) Do you feel strained when you are around your relative?	0	1	2	3	4
4) Do you feel uncertain about what to do about your relative?	0	1	2	3	4

# Positive Aspects of Caregiving

Figure 55. Sense of Purpose



# Positive Aspects of Caregiving

- 73% of caregivers found 1 PAC
- Another 7% had >1 PAC
- 23% companionship
- 22% fulfilling/rewarded
- 13% enjoyment
- 10% satisfied feeling of duty
- 7% felt provided Quality of Life
- 6% meaningful

Cohen CA, Colantonio A. Int J Geriatr Psychiatry 2002



# Positive Aspects of Caregiving

- The research that has been conducted demonstrates that many Caregivers cope well with the challenges they face and experience caregiving as a rewarding and satisfying experience

(Cohen, Colantonio, & Vernich, 2002)



# Positive Aspects of Caregiving

- Caregivers who report higher levels of PAC report lower levels of depression and anxiety as well as fewer feelings of being affected by the behavior of the BFF

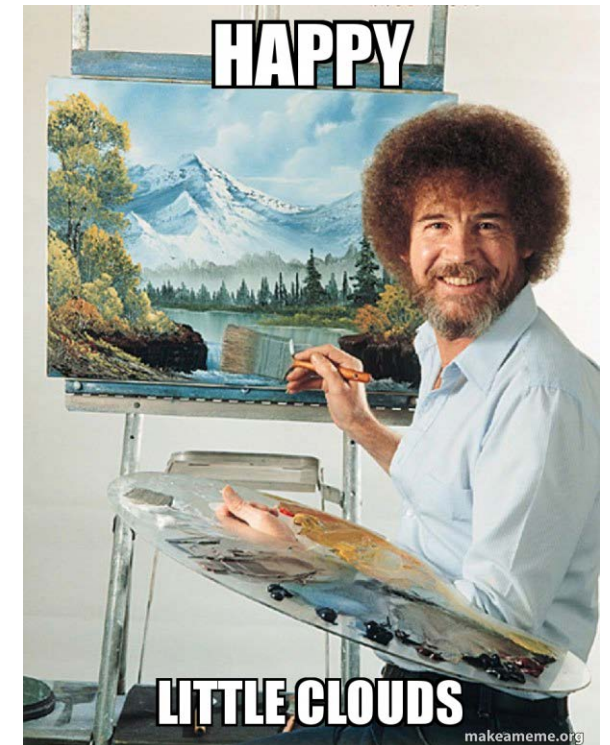
(Mausbach et al., 2006; Pinguart & Sorensen, 2004)



# Positive Aspects of Caregiving

- The ability to find meaning in and derive gratification from the Caregiving experience is associated with increased morale and a feeling of being more able to manage

(Hirschfield, 1983)



# Positive Aspects of Caregiving

- Those who reported higher satisfaction with caregiving were also less likely to institutionalize the BFF

(Roff et al., 2004)





# Need for More Studies and Understanding

- Increasingly evident that caregiving is not only associated with negative consequences
- Also has a positive impact on the caregivers
- PAC is a less researched area compared with that of burden
- The concept of PAC lacks uniformity of definition
- Now being measured in research with several tools





# 10 TIPS FOR FAMILY CAREGIVERS



Seek support from other caregivers. You are not alone!



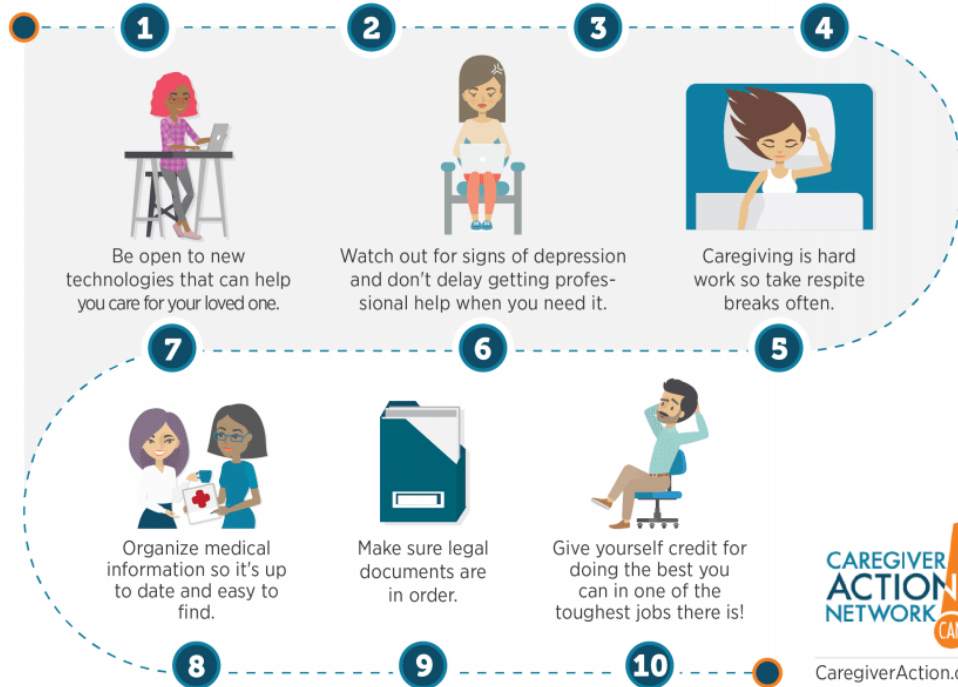
Take care of your own health so that you can be strong enough to take care of your loved one.



Accept offers of help and suggest specific things people can do to help you.



Learn how to communicate effectively with doctors.



# 10 Tips to Polish the Rainbow

- Seek support from other caregivers. You are not alone!
- Support groups
- Churches
- Alzheimer's Association helpline: 800-272-3900
- Parkinson's Association: [parkinsonshawaii.org](http://parkinsonshawaii.org)
- Project Dana: email [cgsg@projectdana.org](mailto:cgsg@projectdana.org)



# 10 Tips to Polish the Rainbow

- Take care of your own health so that you can be strong enough to take care of your loved one
- Schedule doctor appointments, grooming and “down-time”



# 10 Tips to Polish the Rainbow

- Accept offers of help and suggest specific things people can do to help you
- Let's practice saying "Yes" to offers of help





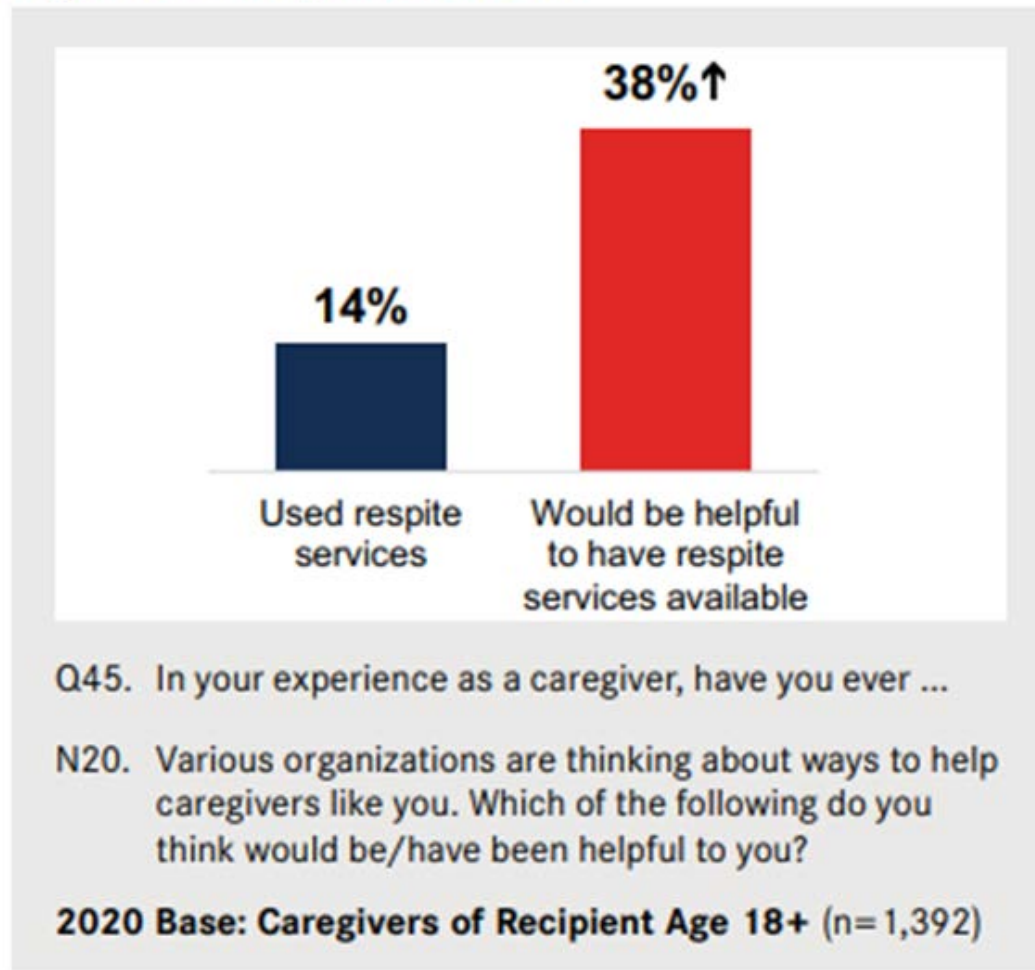
# 10 Tips to Polish the Rainbow

- Learn how to communicate effectively with doctors
- Learn about the disease process
- 3x5 card technique
- Telehealth
- MyChart



# 10 Tips to Polish the Rainbow

**Figure 78. Respite Services**



- Caregiving is hard work so take respite breaks often
- Investigate insurance coverage
- Use paid or unpaid help



# 10 Tips to Polish the Rainbow

- Watch out for signs of depression and don't delay getting professional help when you need it



# 10 Tips to Polish the Rainbow

- Be open to new technologies that can help you care for your loved one
- Coordinating care, calendars, medication management
- Webcams
- Online communities, education
- GPS monitors, remote patient monitoring
- Brain Games



# 10 Tips to Polish the Rainbow

- Organize medical information so it's up to date and easy to find
- Medication list
- Make sure notes are shared between all providers



# 10 Tips to Polish the Rainbow

- Make sure legal documents are in order



## HAWAII DURABLE POWER OF ATTORNEY

### IMPORTANT INFORMATION

This power of attorney authorizes another person (your agent) to make decisions concerning your property for you (the principal). Your agent will be able to make decisions and act with respect to your property (including your money) whether or not you are able to act for yourself.

The power of attorney does not authorize the agent to make medical and health care decisions for you. You should select someone you trust to serve as your agent. Unless you specify otherwise, generally the agent's authority will continue until you die or revoke the power of attorney or the agent resigns or is unable to act for you.

Your agent is entitled to reasonable compensation unless you state otherwise in the Special Instructions. This form provides for designation of one agent. If you wish to name more than one agent, you may name a co-agent in the Special Instructions. Co-agents are not required to act together unless you include that requirement in the Special Instructions.

If your agent is unable or unwilling to act for you, your power of attorney will end unless you have named a successor agent. You may also name a second successor agent.

This power of attorney becomes effective immediately unless you state otherwise in the Special Instructions.

**If you have questions about the power of attorney or the authority you are granting to your agent, you should seek legal advice before signing this form.**

### DESIGNATION OF AGENT

I, \_\_\_\_\_ of \_\_\_\_\_ (Address), authorize \_\_\_\_\_ (Address), as my agent (attorney-in-fact) to act for me and in my name and for my use and benefit. If my agent is unable or unwilling to act for me, I name \_\_\_\_\_ (Address) as my successor agent.



# 10 Tips to Polish the Rainbow



- Give yourself credit for doing the best you can in one of the toughest jobs there is!

# Resources

- Rosalyn Carter Institute
- CDC
- Alzheimer's Association
- ACP Practice Resources
- AARP
- National Alliance for Caregiving (NAC): [www.caregiving.org](http://www.caregiving.org)



# Mahalo

