



advocacy | action | answers on aging

engAGED

The National Resource Center
for Engaging Older Adults

Alone Together: Understanding Social Isolation in Caregiving in the U.S. 2020

C. Grace Whiting, J.D., President and Chief Executive Officer

National Alliance for Caregiving

July 20, 2020

Webinar Instructions

- **Audio options**
 - Use your computer speakers, **OR**
 - Dial in to the conference call
 - Participants are muted
- **“Questions” box**
 - Q&A session will be at the **end** of the presentation, but feel free to submit your questions at any time during the presentation. Click on the dropdown arrow icon “▼” to pop out the questions box where you can type and submit your questions.
- **Technical issues**
 - Due to increased demand on tele-work platforms, we may experience technical issues during the webinar. We assure you we are working to mitigate and correct any possible interference.



The screenshot displays the GoToWebinar interface. At the top, there is a menu bar with 'File', 'View', and 'Help'. Below it, the 'Audio' panel is visible, featuring a 'Sound Check' indicator and two radio buttons: 'Computer audio' (selected) and 'Phone call'. A microphone icon is shown with the word 'MUTED' in orange. Below this, there are dropdown menus for 'Transmit (Plantronics Savi 7xx-M)' and 'Receive (Plantronics Savi 7xx-M)'. A volume bar is also present. The 'Talking:' section indicates 'Liz Davis'. Below the audio panel is the 'Questions' panel, which has a dropdown arrow icon in the top right corner. The main area of the questions panel contains a text input field with the placeholder text '[Enter a question for staff]' and a 'Send' button on the right. At the bottom of the interface, there is a footer section with the text 'Webinar Housekeeping' and 'Webinar ID: 608-865-371', followed by the GoToWebinar logo.

Presenter

C. Grace Whiting, J.D.

President and Chief
Executive Officer, National
Alliance for Caregiving





—

Alone Together: Understanding Social Isolation and Loneliness in *Caregiving in the U.S. 2020*

July 20, 2020

C. Grace Whiting, J.D.
President and CEO
National Alliance for Caregiving

Presentation for:
engAGED: The National Resource Center for
Engaging Older Adults, National Association of
Area Agencies on Aging (n4a)

AARP
Family Caregiving™

naac
National Alliance for Caregiving

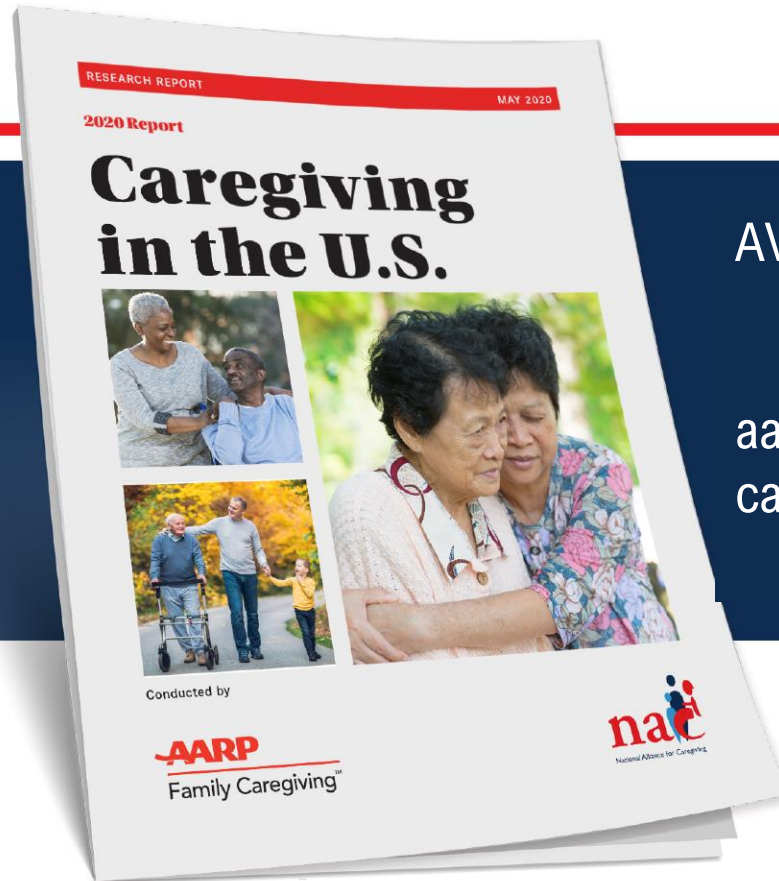
(C) 2020 National Alliance for Caregiving and AARP, Caregiving in the U.S. 2020; visit caregiving.org/caregiving-in-the-us-2020; aarp.org/caregiving; and aarp.org/ppi/info-2020/caregiving-in-the-united-states.html

ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

- Established in 1996, NAC is a 501(c)(3) non-profit organization dedicated to advancing family caregiving through research, innovation, and advocacy
- National coalition of 60 organizational members, including non-profits, corporations, and federal agencies
- Advocacy network representing approximately 30 states/local grassroots communities
- Global leadership as founder of the International Alliance of Carer Organizations (IACO)



About This Report



AVAILABLE TO DOWNLOAD AT:

aarp.org/caregiving
caregiving.org/caregiving-in-the-us-2020

AARP
Family Caregiving™

nac
National Alliance for Caregiving

Made Possible By

Independent Advisory Panel

María P. Aranda, PhD, Associate Professor and Executive Director, USC Edward R. Roybal Institute on Aging, USC Suzanne Dworak-Peck School of Social Work

Joseph E. Gaugler, PhD, Robert L. Kane Endowed Chair in Long-Term Care and Aging and Professor, School of Public Health, University of Minnesota

Carol Levine, MA, Senior Fellow, United Hospital Fund, New York City (former Director of UHF Families and Health Care Project)

Feylyn Lewis, PhD, Research Fellow, University of Sussex

David Lindeman, PhD, Director Health, Center for Information Technology Research in the Interest of Society (CITRIS), UC Berkeley; Director, Center for Technology and Aging (CTA)

Nancy E. Lundebjerg, MPA, Chief Executive Officer, American Geriatrics Society

Steve Schwab, CEO, Elizabeth Dole Foundation (with special thanks to Laurel Rodewald)

Regina A. Shih, PhD, Senior Policy Researcher, RAND Corporation

The research was conducted by Greenwald & Associates (www.greenwaldresearch.com) with study direction by Lisa Weber-Raley, Senior Vice President, and project support from Karina Haggerty, Rashanda McLaurin, and Christina Baydaline.

THIS REPORT WAS MADE POSSIBLE WITH GENEROUS SPONSORSHIP FROM



The John A. Hartford Foundation



Methodology

- **Nationally representative**, quantitative online surveys
- Captures perspectives from **1,392 caregivers age 18+**
- Utilized Ipsos' (formerly Gfk) national, probability-based, online KnowledgePanel® as was used in the 2015 wave
- Data collected for *Caregiving in the U.S. 2020* allowed **full online survey responses** from caregivers of adults and caregivers of children with special needs under age 18
 - *However, the main study summarizes the findings for those caring for adults (age 18+) only*
- **Margin of error is +/- 2.5** percentage points at the 95% confidence level
 - This means that 95 times out of 100, a difference of greater than roughly 2.5 percentage points would not have occurred by chance.
- Significant increases or decreases are displayed in the graphics as the percentage point change from 2015 to 2020 and with arrows

The Big Picture

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



↑ **21%** refers to the prevalence of caregiving for all ages

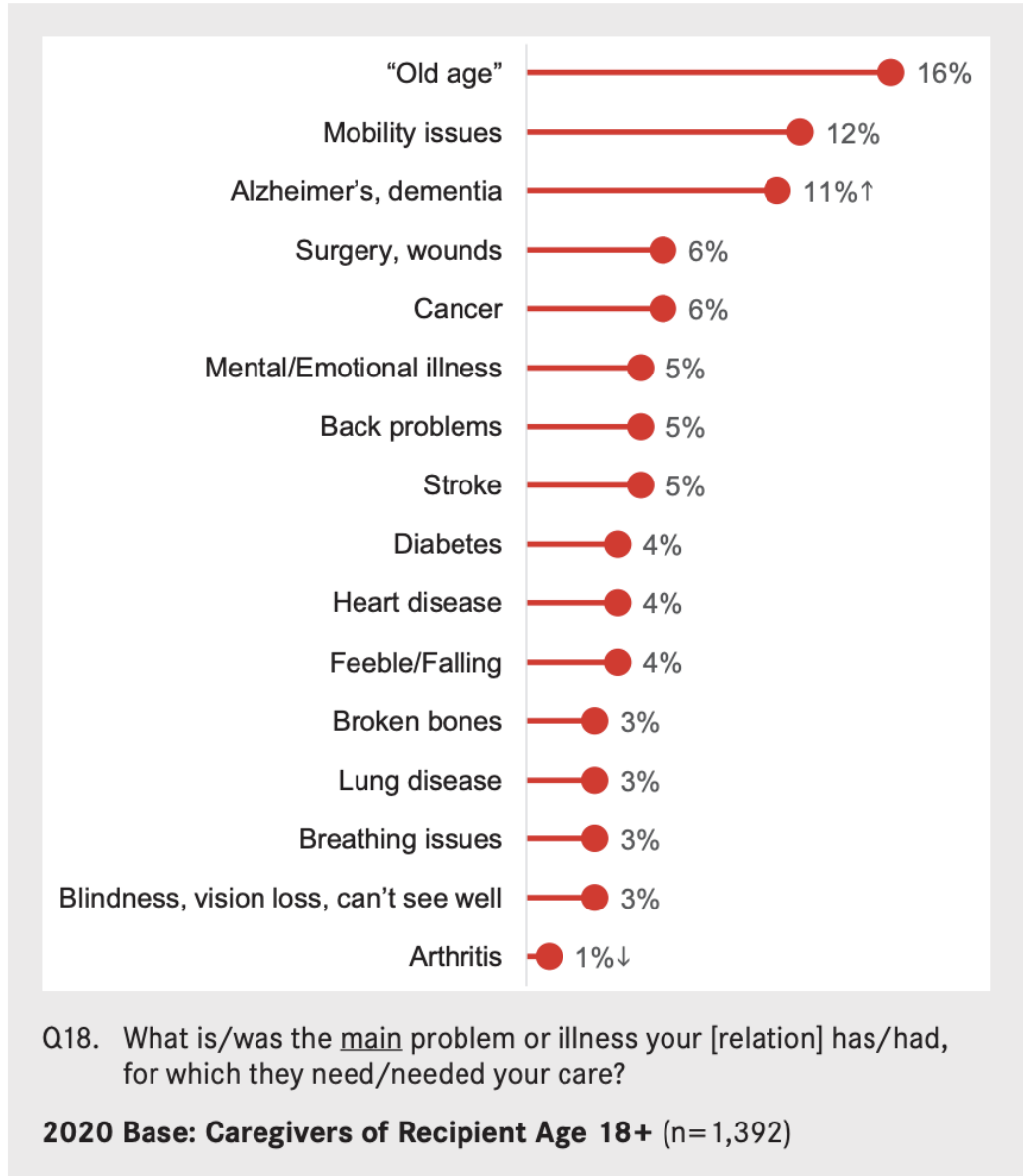
↑ **More are caring for 2 or more people** (up to 24% from 18% in 2015)

↑ **More are caring longer, on average 4.5 years**, with nearly a third (29%) reporting that they're caring for someone 5 years or more (up 5% from 2015)

↑ **More are caring in general**, with 9.5 million new caregivers compared to 2015

Main Problem or Illness

Figure 25. Care Recipient's Main Problem or Illness

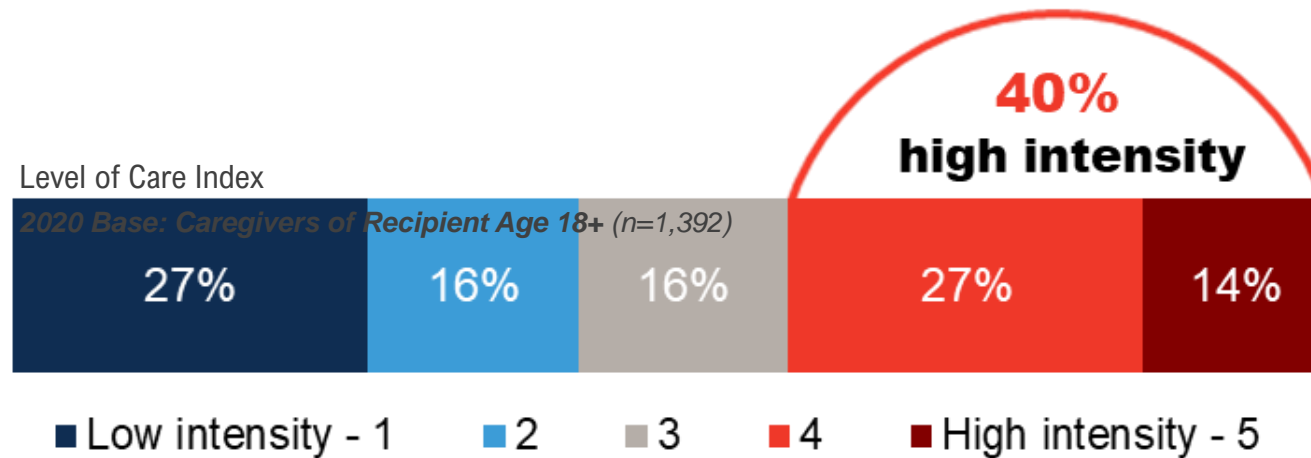


Trends in Caregiving: Longer Care Journeys

- On average, caregivers spend **4.5 years** caring for their recipient
- **Most are caring longer**, with nearly a third (29%) caring for more than 5 years, up from 24% in 2015
- Caregivers spend **23.7 hours** per week providing care
 - One in five (21%) caregivers care 40+ each week
- Caring because of **chronic conditions**:
 - ↑ Memory problem, such as dementia
(32% of caregivers, up 6% from 2015)
 - ↑ Emotional/mental health issues
(27%, up 6% from 2015)
 - ↑ Multiple conditions
(45%, up 8% from 2015)



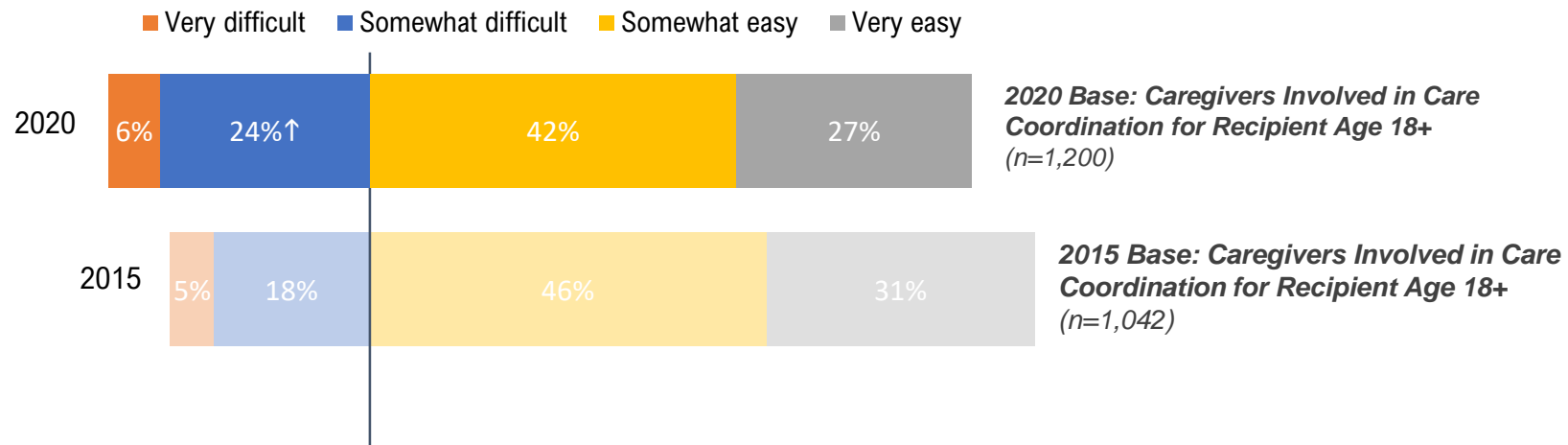
Trends in Caregiving: High Intensity Care



Noteworthy: Younger caregivers (ages 18 to 49) are more often in a high intensity care situation (43%) compared to 2015 (36%)

Trends in Caregiving: Challenges Coordinating Care

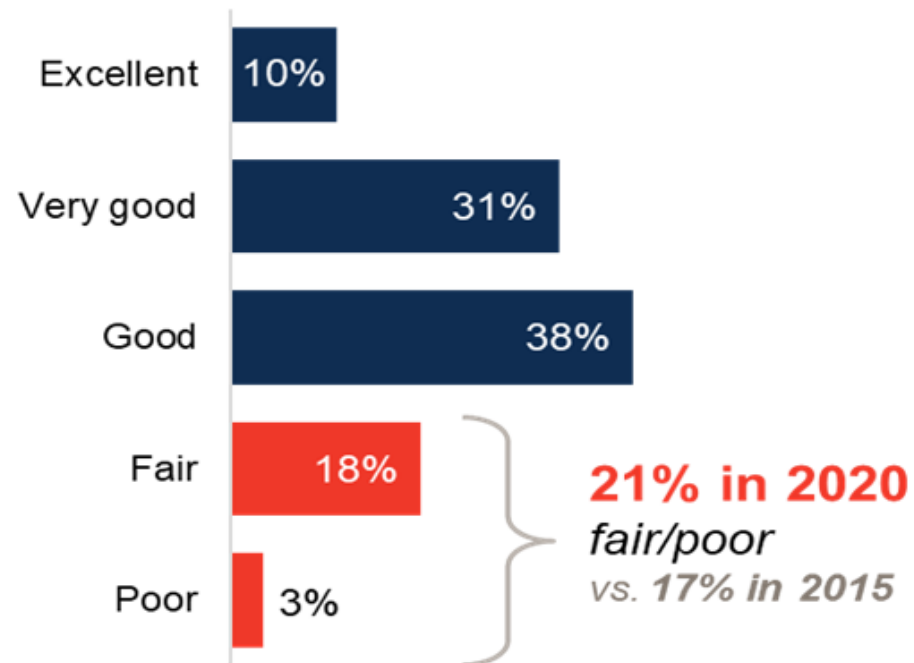
Q38. (If responsible for coordinating) Please think about all of the health care professionals or service providers who give/gave care or treatment to your [relation]. How easy or difficult is/was it for you to coordinate care between those providers?



Trends in Caregiving: Caregiver Health and Wellbeing

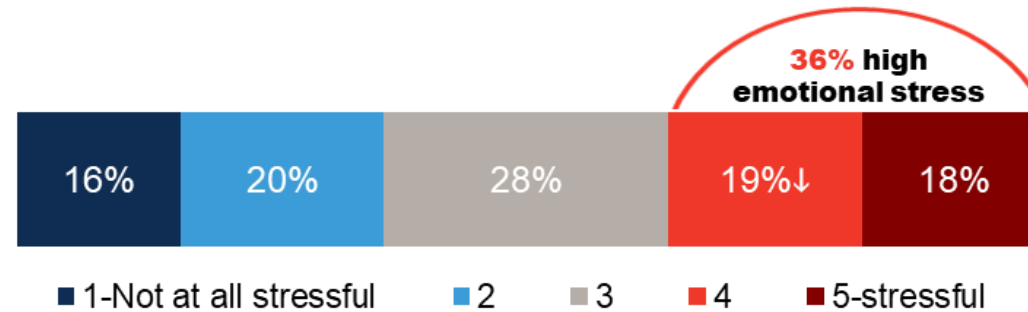
D1. How would you describe your own health? / When you were last caregiving, was your health ...?

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



Trends in Caregiving: Mixed Emotions

MEAN 3.0



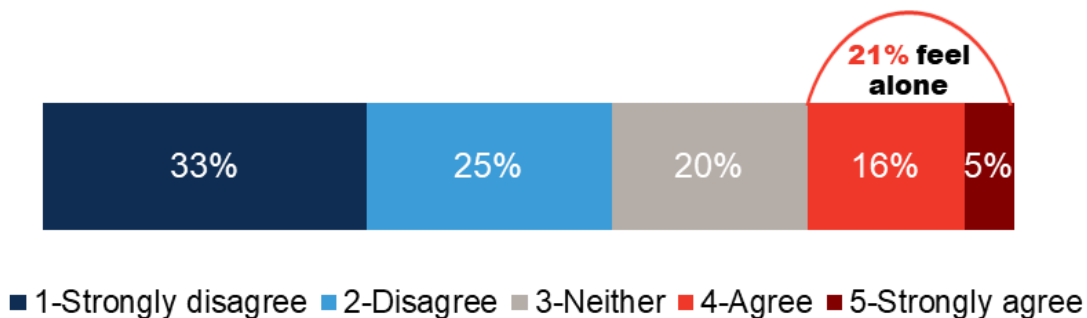
Q36. How *emotionally* stressful would you say that caring for your [relation] is/was for you?
2020 Base: Caregivers of Recipient Age 18+
(n=1,392)

- Half of caregivers feel their role gives them a sense of purpose in life (51%)

Trends in Caregiving: Feeling Alone

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

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



- One out of five caregivers of adults feel alone
- 22% of those caring one to four years, and 32% of those caring five or more years feel alone (compared to 14% of those caring for less than a year)

The “Typical” Isolated Caregiver

- 49.6 years old, on average
- More often a **woman**, and less often married/ partnered (than those who do not feel alone)
- Typically **cares for a 68-year-old relative**; about half the time their own parent
- The recipient typically has **multiple conditions**:
 - A long-term physical condition
 - An emotional/mental health condition
 - A behavioral problem.
- They are usually the **sole unpaid caregiver** (60% vs 43% who do not feel alone)
- Few report having paid help (23% vs 34% who do not feel alone).



The Isolated Caregiver: A Day in the Life



- **Caring for nearly six years (5.9) on average**
 - Compared to an average of 3.9 for those who do not feel alone
- **More than half live in the same house as the person who needs care (54%)**
 - Compared to 34% who do not feel alone
- **Most are in a “high-intensity” care situation:**
 - Average of 33 hours a week
 - Helping with 1.9 ADLs and 4.9 IADLs
- **Care can be challenging**
 - 4 out of 10 (39%) report difficulty helping with those ADLs
 - Compared to 14% who do not feel alone

The Isolated Caregiver: **Work and Finance**

- **Most work in addition to caring**, an average of 37 hours each week
- More likely to experience **job-related impacts** than those who do not feel alone, such as:
 - taking time off work
 - cutting back work hours
 - receiving a warning for attendance
- Most have had at least one **financial impact**:
 - Stopping saving
 - Taking on more debt
 - Leaving bills unpaid or paying them late



The Isolated Caregiver: Challenges to Health and Wellbeing

- Nearly three out of four have **high stress (72%)**
 - Compared to 24% of those who do not feel alone
- Nearly forty percent reported **physical strain (37% high strain vs. 11%)**
- Many had **worsening health (30% rate their health fair/poor vs. 16%)**
 - Challenges to **taking care of their own health (58% vs. 11%)**
 - Feeling **health has declined** as a result of caregiving (50% vs. 13%)
- More likely to **anticipate caregiving for the next 5 years (62% vs. 52%)**
- Most feel they had **no choice** in taking on this responsibility
 - 73% vs. 44% who do not feel alone



The Isolated Caregiver: **Service and Supports**

- More often **want help managing their own emotional and physical stress** and their own **personal finances**.
- Find it **more difficult to coordinate care** between their recipient's providers (40% vs. 21% who do not feel alone)
- Find it **difficult to get affordable services** in their care recipient's community (46% vs. 21% who do not feel alone)
- They **often reach out for help**:
 - **Searching online** for support services, aides, facilities, or other assistance for their care recipient
 - More often **using technology** to help them with tasks like tracking their recipient's finances and personal health records.

The Isolated Caregiver: **Helpful Policies**



- They would appreciate **any kind of financial support policies**
 - Income tax credits
 - Payment for some hours of care
 - Partially paid leave from work
- **Nearly half (47%) want access to respite, and they're more likely to want respite than others**
 - 47% compared to 35% of those who do not feel alone



Hot Topic:
Understanding
Social Isolation in a Time
of Physical Distance

COVID-19:

Often Little Support for “Typical” Challenges



Typical* Caregiving Challenges

- Living together vs. long-distance or facility-based care
- Helping with activities of daily living, care coordination, medical/nursing tasks
- Emotional strain on relationships with the person receiving care, other family or friends
- Financial strain, deferred career or educational goals
- Worsening physical health of the caregiver



COVID-19: A Disruptive Influence



- Uncertainty of disease impact and timeline, which increases caregiver stress
- Quarantine/limits on visiting family members, especially in advanced illness
- Closure of dependent care and childcare supports
- Potential job loss, long-term career and income security damage
- Restricted access to medicine, equipment, and care providers
- Increased concern about self-care and health, worry, anger, anticipatory anxiety and grief

COVID-19: The “Typical” Caregiving Journey



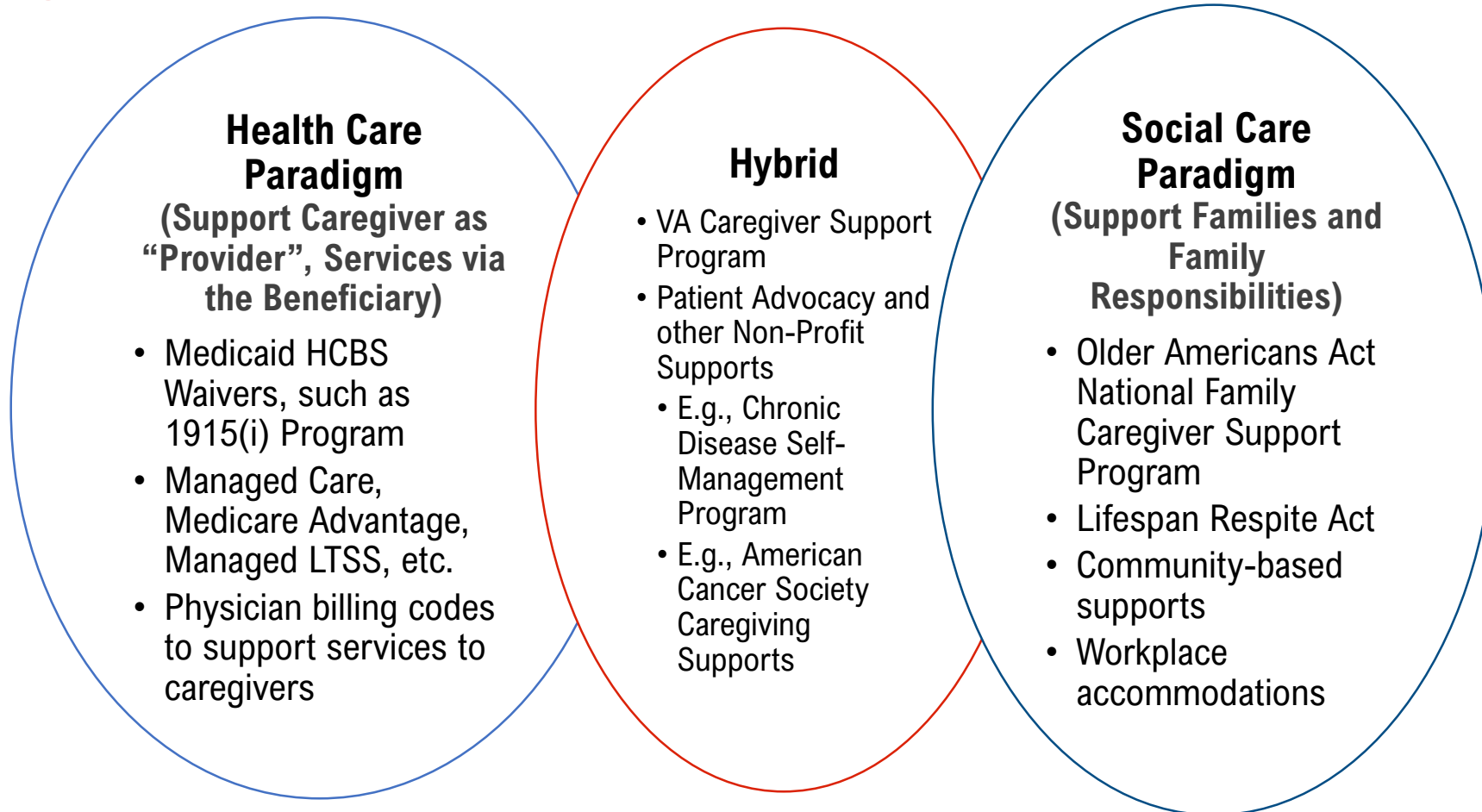
**This is for illustration only. While generally this principle may hold true in chronic conditions such as diabetes or dementia, the main problem or illness requiring care may change over time or coexist with other chronic conditions, injury, or disease. In conditions that are relapsing/remitting condition (such as cancer, autoimmune disorders), or conditions where the disease journey is unclear (such as rare and orphan disorders).*

COVID-19: The Pandemic Creates **New Uncertainty** in the Caregiving Journey and **New Caregivers**

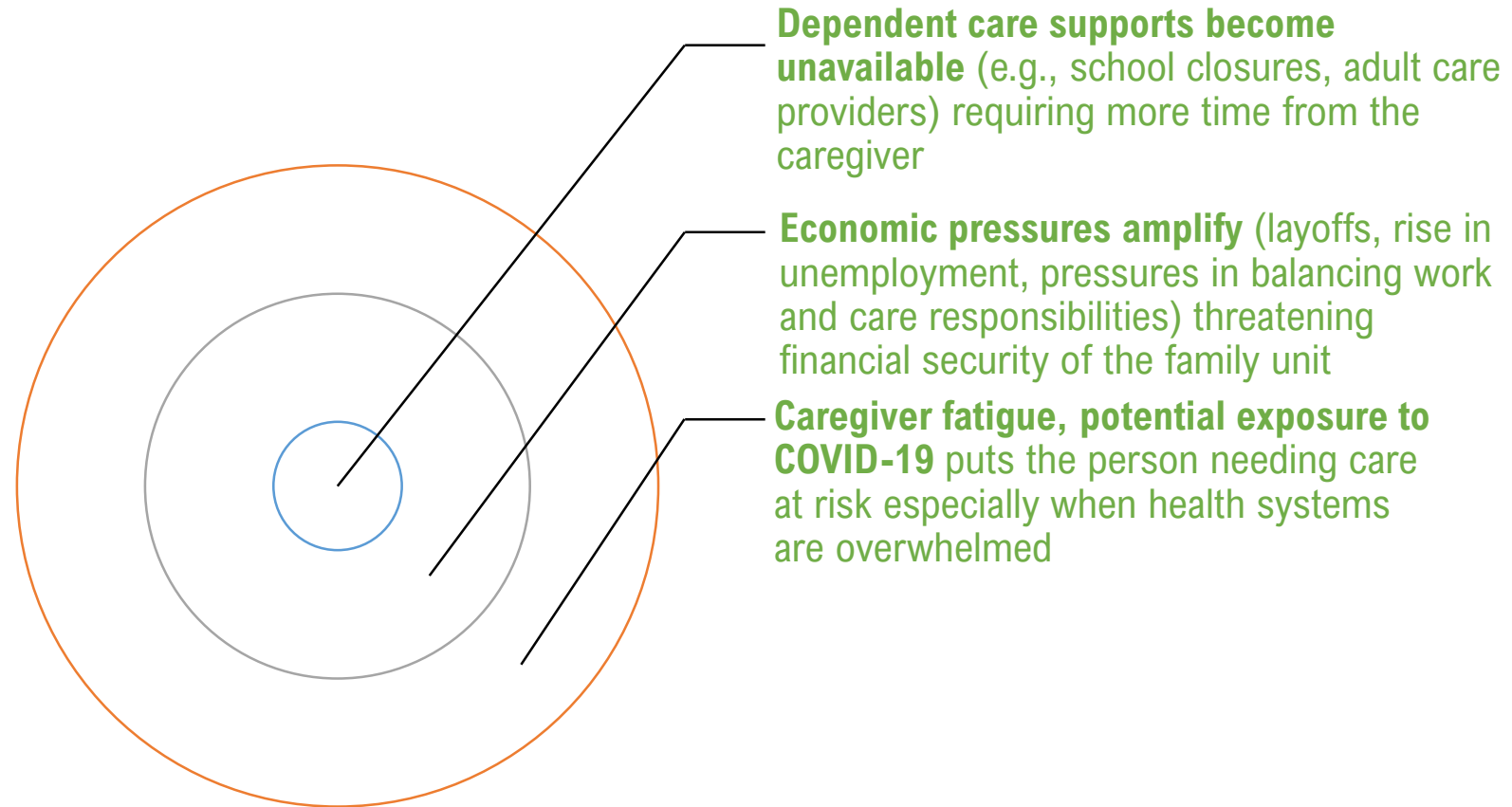


**This is for illustration only. While generally this principle may hold true in chronic conditions such as diabetes or dementia, the main problem or illness requiring care may change over time or coexist with other chronic conditions, injury, or disease. In conditions that are relapsing/remitting condition (such as cancer, autoimmune disorders), or conditions where the disease journey is unclear (such as rare and orphan disorders).*

COVID-19: Even Before COVID-19, We Faced Siloed Systems of Support



COVID-19: Supply/Demand Challenges



COVID-19:

Developing **a New Framework** for Caregivers

- Describe the **impact of COVID-19 on family caregivers**
- **Collect evidence-informed tools and information** for families that provides knowledge about caring for someone:
 - Who are co-resident but cannot go to a facility for risk of contagion
 - Who are physically distant and should be incentivized to stay at home
- Push people of influence to **include caregivers as partners**– and to provided support when other help is needed
 - Federal, state, and local policymakers
 - Innovators and private enterprise
 - Professionals who work with caregivers

Spirited Discussion

Learn more at
www.caregiving.org



National Alliance for Caregiving



engAGED National Resource Center

- National effort to increase social engagement among older adults
- Administered by the National Association of Area Agencies on Aging (n4a)
- Project partners:
 - Generations United,
 - National Center for Osher Lifelong Learning Institutes
 - Older Adults Technology Services
- Funded by the U.S. Administration on Aging, which is part of the Administration for Community Living

COVID-19 Innovations from the Field

- Caregiver Social Isolation
- Telephone Reassurance and Wellness Checks
- Remote Connectedness
- Virtual Wellness Programming
- Engaging Older Adults at Home
- Transportation and Social Isolation
- Caregiver Social Isolation


Other Recent resources:

- Staying Connected At Home During COVID-19 (flyer)
- New additions to blog, social media, newsletter

<https://www.engagingolderadults.org/>

Coming Soon!

Blog post templates to engage older adults and caregiver during COVID-19 (sample language for AAAs and other providers)



Blog Post Templates to engAGE Older Adults and Caregivers During COVID-19

As the COVID-19 crisis continues to affect older adults around the country, engAGED has developed a six-part series of sample blog posts intended to help organizations working with older adults encourage them to stay active, engaged and connected in their communities during the COVID-19 pandemic. Our goal is for organizations to use this information in their own messaging, resources and outreach that can help them better meet the needs of older adults in their communities during these changing times. For more resources, please visit www.engagingolderadults.org/covid19.

engAGED
The National Resource Center for Engaging Older Adults

n4a
National Association of Area Agencies on Aging

ACL
American Council on Aging

Find us here:

- www.engagingolderadults.org
- Facebook: @engAGEDCenter
- Twitter: @engAGEDCenter

Questions?

Please use the questions tab in your
Go To Webinar module to submit your question.

Thank you for attending today's webinar!



advocacy | action | answers on aging

The recording will be available on:
<https://www.engagingolderadults.org>