



COVID-19 PANDEMIC Considerations for Caregiving Advocates

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National Alliance for Caregiving

The COVID-19 pandemic is a rapidly changing public health crisis and information is not exhaustive. For the latest information, please visit <https://www.cdc.gov/coronavirus/>.

ABOUT NAC

Established in 1996, NAC is a 501(c)(3) non-profit organization dedicated to improving the quality of life for family caregivers and those in their care, 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)

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National Alliance for Caregiving

DEFINING “CAREGIVER”

From the RAISE Family Caregivers Act
P.L. No: 115-119):

“The term 'family caregiver' means an adult **family member or other individual** who has a **significant relationship with**, and who **provides a broad range of assistance** to, an individual with a **chronic or other health condition, disability, or functional limitation.**”



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CAREGIVING & COVID-19



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IN OUR CURRENT WORLD, CHRONIC DISEASE, DISABILITY, CARE NEEDS CAN **STRAIN FAMILIES**



Illustration from C. Grace Whiting, President/CEO, National Alliance for Caregiving drawing on research from Dr. Frances Lewis and Taking Care of Her, see Lewis, F., Alzawad, Z., Griffith, K., Almulla, H., Wu, P., Chi, N., Zahlis, E. & Shands, M. (2017) Taking care of her: A pilot feasibility study of a caregiver intervention for women with advanced-stage ovarian cancer. Journal of Cancer Therapy, 8, 472-489. DOI: [10.4236/jct.2017.85041](https://doi.org/10.4236/jct.2017.85041). See also, TedX Talks. (2016, January 12), Caring for the caregivers | Frances Lewis | TEDxSnolsleLibraries [video]. Youtube. <https://youtu.be/duhJHedj82g>. See also, LinkedIn Post: <https://www.linkedin.com/pulse/what-family-caregivers-can-teach-us-resilience-crisis-whiting/>.

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CAREGIVER SUPPORTS CAN REFRAME “YOU VS. ME” TO “US VS. DISEASE”



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TODAY, THERE'S LITTLE SUPPORT TO MANAGE “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



See *Caregiving in the U.S. 2015*, National Alliance for Caregiving and AARP Public Policy Institute, at <https://www.caregiving.org/research/caregivingusa/>

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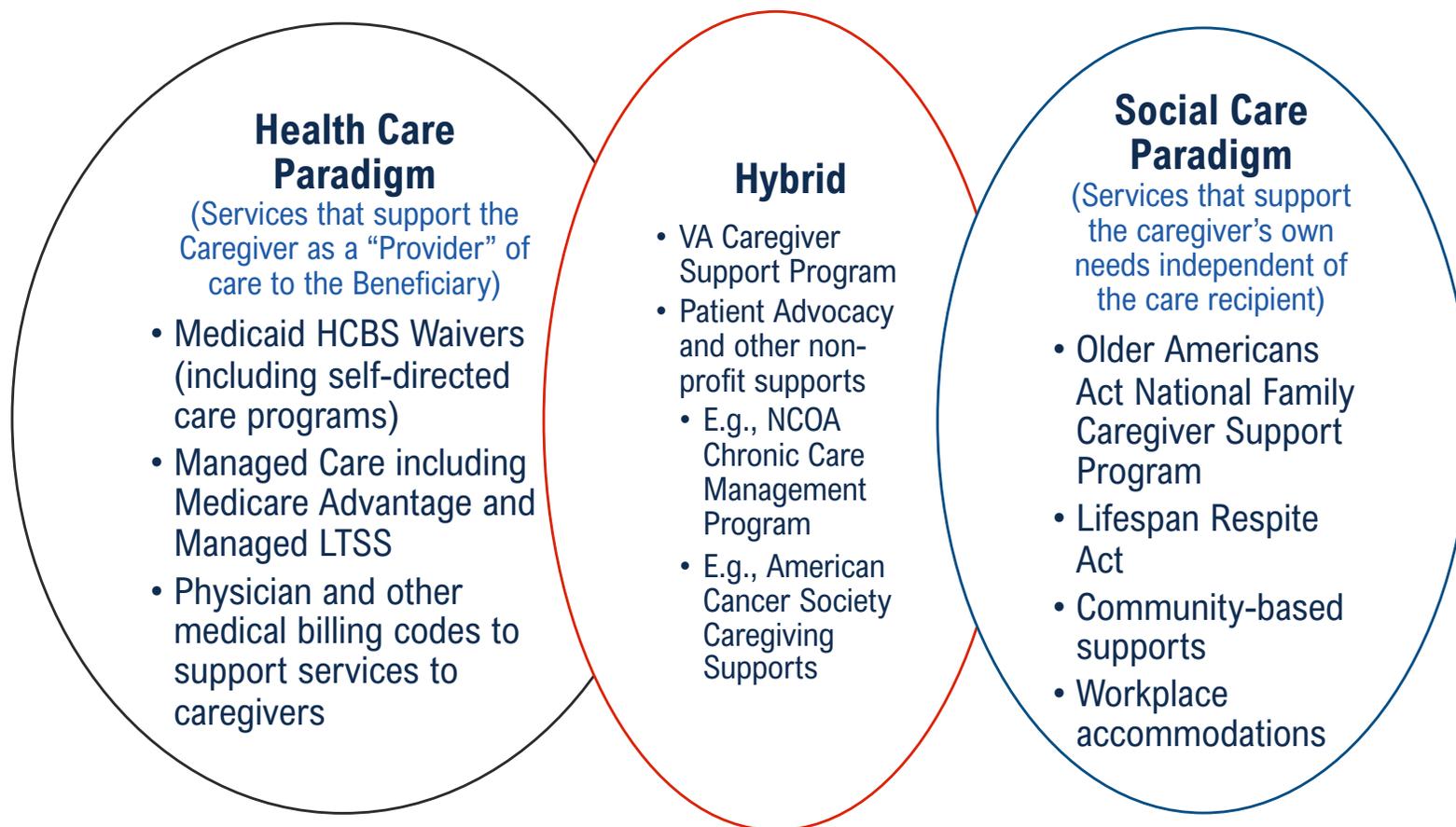
CHALLENGE 1: “TYPICAL” CHALLENGES + COVID-19



- 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

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SUPPORTS ARE “SILOED” & HARD FOR FAMILIES TO NAVIGATE



National Alliance for Caregiving – For illustration only.

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“TYPICAL” CAREGIVING OFTEN INTENSIFIES OVER TIME* ALONG A WELL-ESTABLISHED DISEASE 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).*

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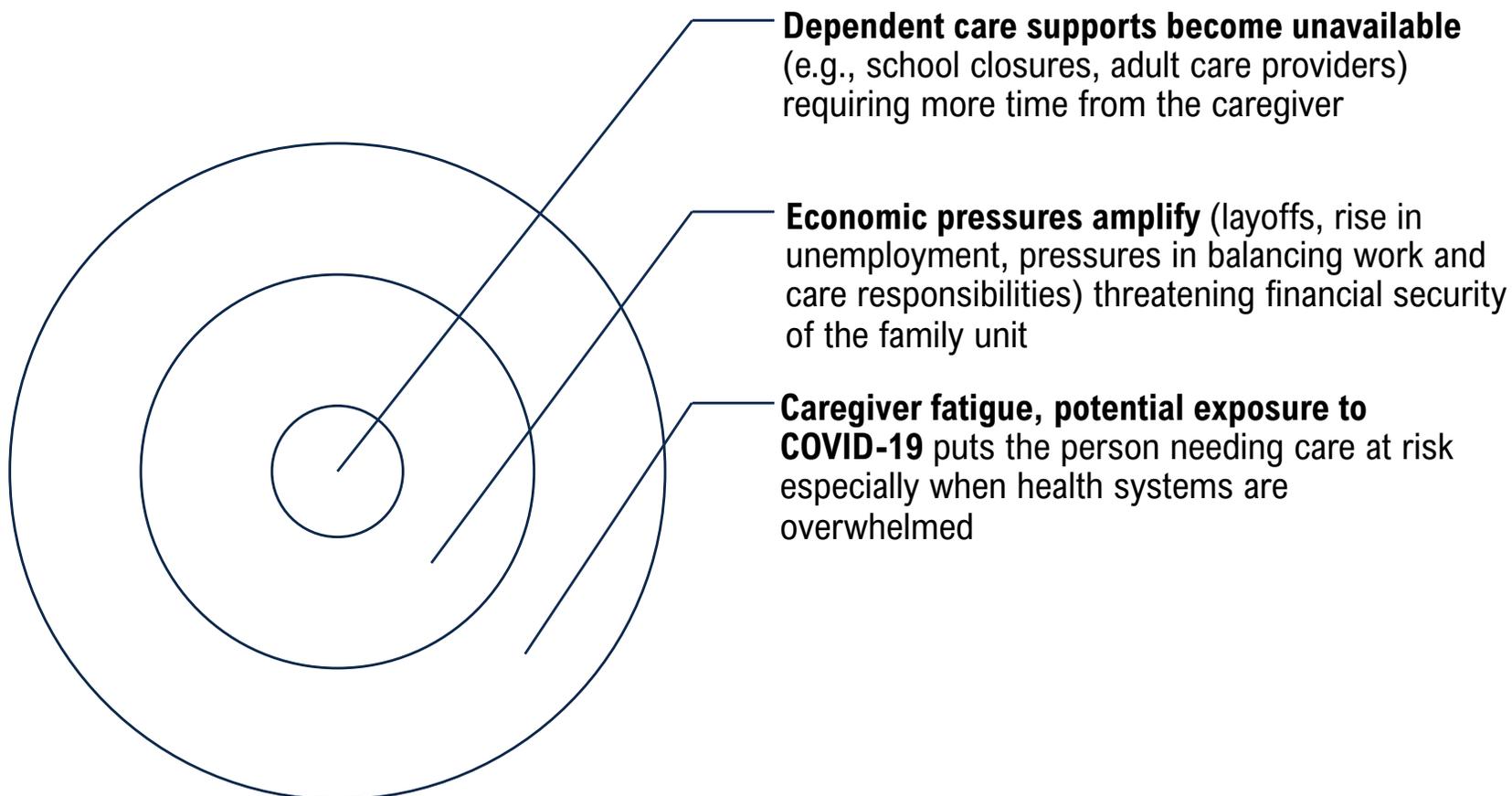


COVID-19 CHALLENGE 2: THE PANDEMIC CREATES **NEW UNCERTAINTY** IN THE CAREGIVING JOURNEY **AND NEW CAREGIVERS**



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SUPPLY/DEMAND CHALLENGES: CARE PROVIDERS



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POTENTIAL POLICY IMPLICATIONS FOR CAREGIVERS OF COVID-19

Workplace

- Emergency paid family and medical leave
- Emergency paid sick days
- Job protections for sick workers and for caregivers
- Availability of telework, remote work

Income Security

- Extended unemployment benefits
- Economic stimulus
- Home- and community-based supports for daily needs

Care Management

- Health information on managing:
 - COVID19 in otherwise healthy individuals
 - Risk in those who need care
- Technology to ease social isolation, foster shared-decision making

Home-Based Care

- Easing of Medicare home health regulations
- Easing of telehealth restrictions
- Easing of Home- and Community-Based Waivers and self-directed care programs

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HEALTH INFORMATION RESOURCES

Federal Health Information Resources

- [CDC – Protect Your Family](#)
- [CDC – Protect Your Home](#)
- [CDC – Manage Anxiety & Stress](#)
- [National Institutes of Health COVID-19 Resources](#)

Information for Employers

- [Department of Labor on COVID-19 and the American Workplace](#)
- [Comprehensive FAQs for Employers](#) (via Fisher Phillips)
- [Legal Alerts on COVID-19 – Including State by State Information](#) (via Fisher Phillips)

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COMMUNITY CAREGIVING RESOURCES

Caring Across Generations and National Alliance for Caregiving
[Tips for Sandwich Generation Caregivers in the Era of COVID-19](#) (PDF)

[AARP Resources on COVID-19](#)

[Alzheimer's Association – Coronavirus \(COVID-19\): Tips for Dementia Caregivers](#)

[Alliance for Aging Research](#)

[Common Questions About COVID-19 for Older Adults and People with Chronic Health Conditions](#)

[American Cancer Society](#) – Information for Cancer Caregivers

ARCH National Respite Coalition – [Caregiving and Respite in the Time of COVID-19](#)

[Caregiver Action Network – Caregiver Help Desk](#), or call 855-227-3640, 8:00 AM – 7:00 PM ET

Elizabeth Dole Foundation – [COVID-19 Hidden Heroes Resource Hub](#)

Family Caregiver Alliance – [COVID-19 Resources and Articles for Family Caregivers](#)

Mental Health America - [COVID-19 Information](#)

Rosalyn Carter Institute – [Caring During COVID-19](#)

The John A. Hartford Foundation

[Coronavirus Disease Resources for Older Adults, Family Caregivers, and Health Care Providers](#)

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THANK YOU

FOR MORE INFORMATION, PLEASE VISIT
WWW.CAREGIVING.ORG