

Care and Career Support: Health Systems to Employers



How can we assist caregivers today?

Goals of Webinar

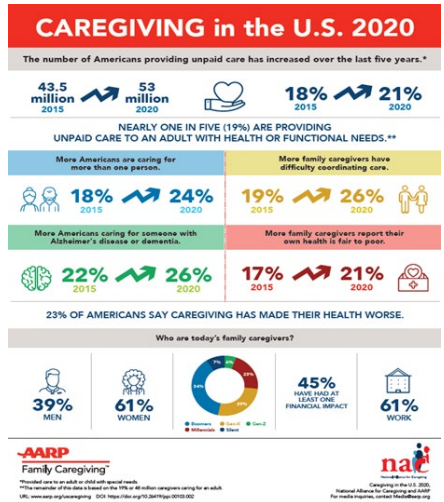
- ✓ Cancer and Caregiving
- ✓ Lived Experience
- ✓ Care & Career Support Solutions
 - ✓ Health Systems
 - ✓ Employers and Employees

Cancer Landscape

- Worldwide in 2020, 19.3 million new cancer cases and almost 10 million deaths.¹
- >1.9 million new diagnoses expected and >609,000 deaths in 2022 in U.S.²
- 18.1 million cancer survivors in U.S. in 2022 or 5.4% of population and expected to increase to 26 million by 2040.^{3, 4}
 - Survival variations by cancer type
 - Pronounced disparities by race and ethnicity^{5,6}

Caregiving in U.S?

- 53 million adults care for an adult or child
- 47.9 million adults care for an adult
 - 82% are < 65 (\bar{x} = 49.4)
 - 61% female
 - 61% non-Hispanic white; 17% Hispanic or Latino; 14% non-Hispanic African American or Black; 5% Asian American
 - 68% had some college or more
 - > younger caregivers caring for 1+ person



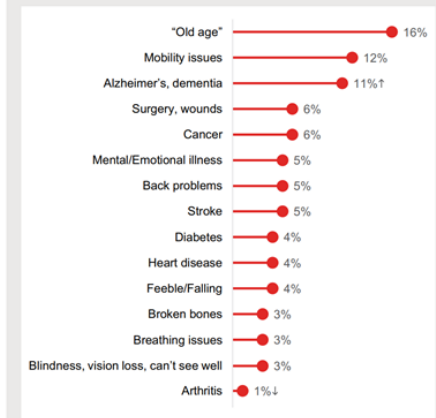
<https://www.caregiving.org/caregiving-in-the-us-2020/>

Cancer Caregiving in U.S.

- 6% of caregivers/~2.8 million care for cancer⁷
- Caregiver demographics^{8*}
 - 58% female
 - 65% white; 16% Hispanic or Latino; 11% African American or Black; 8% Asian American
 - 44% < age 50; 75% < age 65
 - 50% employed
 - 63% some college or >
 - 46% household income <\$50,000
 - 38% of cancer survivors were <65

* 2015 data⁸

Figure 25. Care Recipient's Main Problem or Illness



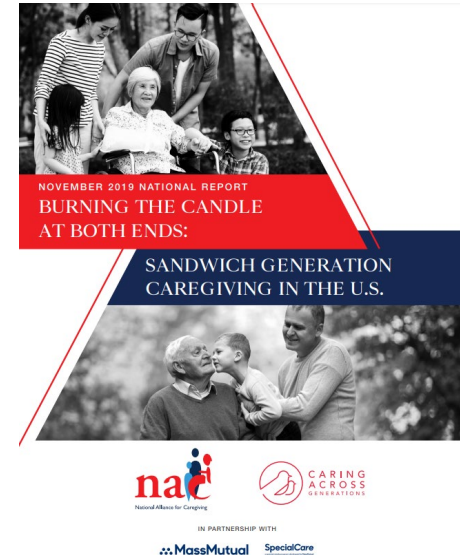
Q18. What is/was the main problem or illness your [relation] has/had, for which they need/needed your care?

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

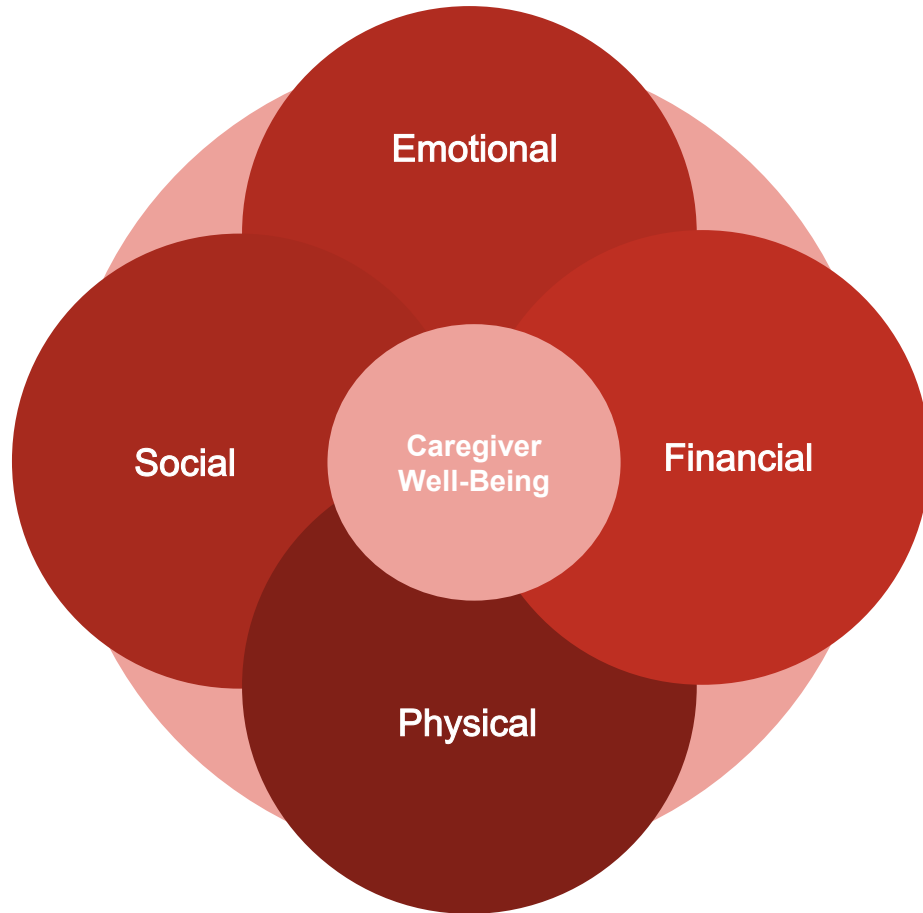
<https://www.caregiving.org/caregiving-in-the-us-2020/>

The Care Experience...

- Common Tasks
 - Practical support
 - Medical or nursing support
 - Communication, advocacy, decision making, and planning
 - Monitor symptoms and side effects
- Considerations
 - Sociodemographic variations^{9, 10}
 - Cancer type and progression¹¹
 - Dual-level (“Sandwich”) caring¹²



<https://www.caregiving.org/research/sandwich-caregiver/>



Varies by care context (even within cancer), disease burden (stage and progression), and sociodemographic factors.^{7, 13, 14, 15}



Medical Out-Of-Pocket Costs

- Cost sharing for cancer care
- Prescription costs
- Loss of insurance
- Caregivers medical costs

Non-Medical Out-Of-Pocket Costs

- Travel (hotel, gas, parking, public transportation)
- Home help
- Child care

Income Loss

- Reduced hours
- Forgone promotions or career development
- Quitting
- Retiring early
- Reduced savings

Absenteeism/ Presenteeism

- Project delays
- Lost productivity

Christina Sisti, DPS, MPH, MS



NCCS CPAT Member, Cancer Survivor and Caregiver



Solutions

Considerations for Health Systems and Employers

Why Health Systems and Employers Together?

- Regular points of contact for survivors and caregivers
- Potential to improve outcomes for caregivers¹⁸ and survivors alike^{19, 20}
- Potential of long-term benefit in health-related spending for systems and employers^{17, 21-22}
- Inter-related

Possible Health System Solutions

- Adopt person- and family-centered models of care
 - Engage caregivers, recognize needs, and resource, especially financial burden^{17, 23-30}
- Assess greater and ongoing use of telehealth for caregiver engagement³¹
 - Advance access to technology
- Ensure comprehensive, equitable care

The Triple Aim: Care, Health, And Cost

The remaining barriers to integrated care are not technical; they are political.

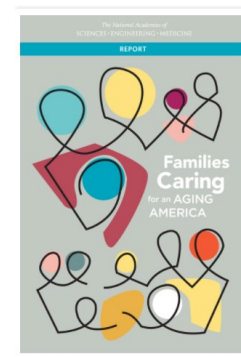
By Donald M. Berwick, Thomas W. Nolan, and John Whittington

ABSTRACT Improving the U.S. health care system requires fundamental pursuit of three aims: improving the experience of care, improving the health of populations, and reducing per capita costs of health care. Preconditions for this include the elevation of an identified population, a commitment to transparency by its members, and the existence of an organization (an “integrator”) that accepts responsibility for all three aims for that population. The integrator’s core activities at least five categories: partnership with individuals and families, redesign of primary care, population health management, financial management, and process system integration. (Health Affairs 27(3):e1, 2008; 27(3):506-511; DOI:10.1377/hlthaff.27(3).756)

Functions Of An Integrator

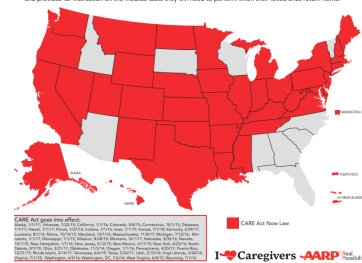
● **Inviting individuals and families.** Pursuit of the Triple Aim requires that the population served become centrally better informed about both the determinants of their own health status and the benefits and limitations of individual health care practices and procedures. An effective integrator would work proactively to change the “more is better” culture through transparency, systematic education, communication, and shared decision making with patients and consumers, rather than by restricting access, shifting costs, or creating administrative barriers to care. Many members of the population, especially those with chronic diseases, will need someone who can work with them to establish a plan for their ongoing care, guide them

HEALTH AFFAIRS | Volume 27 | Number 3 | March 2008 | 756



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.





Assisting Caregivers Today (ACT) Care and Career Checklists

Employee and Employer Checklists

What can I do to get the most employee support while providing care or to plan ahead?

01

Engage with Human Resources

- Schedule a meeting as early as possible

02

Your Care Recipient's
Employer Benefits

- Review access to Employee Assistance Plan benefits (if offered)
- Review Medical Plan benefits for special support programs

03

Adjust Your Work Schedule

- Utilize Time Off balances (vacation, sick, and personal)
- Use a Paid Time Off donation program (if provided)
- Inquire about Flexible Work Arrangements

04

Consider Financial Supports

- Flexible Spending Accounts

05

Plan for Future Caregiving

- Consider engaging early in retirement planning options
- Consider Voluntary Life, Long-Term Care, Critical Illness, and/or Hospital Insurance for self and future care recipients
- Explore Social Security benefits, early payouts on life and retirement benefits

Is your organization offering caregiversupportive policies and programs?

01

Enable a Careand-Career Supportive Culture

- Culture of empathy for caregiving modeled by leadership
- Consider Flexible Work Arrangements
- Paid Time Off donation program
- Consider funding an Emergency Relief Program
- Provide a centralized caregiving support specialist

02

Provide Core Benefits

- FMLA (50 or more employees)
- Paid Leave (State/Local dependent)
- Comprehensive Medical and Prescription plans

03

Offer and Expand Voluntary Benefits for Financial Wellness

- Long-Term Care Insurance
- Critical Illness Insurance
- Retirement - employer matching program

04

Recognize and Provide Psychosocial Support

- Employee Assistance Programs
- Support groups
- Peer mentors



Discussion & Questions



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References

1. Hung, S., Ferlay, J., Siegel, R.L., Laversanne, M., Soerjomataram, I., Jemal, A., Bray, F. (2021). Global cancer statistics 2020: GLOBOCAN Estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin*; 71: 209–249.
2. Siegel, R.L., Miller, K.D., Fuchs, H.E., Jemal, A. (2022). Cancer statistics, 2022. *CA Cancer J Clin*; 72(1): 7-33.
3. Miller, K.D., Nogueira, L., Devasia, T., Mariotto, A.B., Yabroff, K.R., Jemal, A., et al. (2022). Cancer treatment and survivorship statistics, 2022. *CA Cancer J Clin*; epub, June 23.
4. Bluethmann, S. M, Mariotto, A.B., Rowland, J.H. (2016). Anticipating the Silver Tsunami: Prevalence trajectories and comorbidity burden among older cancer survivors in the United States. *Cancer Epidemiol Biomarkers Prev*; 25(70): 1029-1036.
5. Giaquinto, A, N., Miller, K.D., Tossas, K.Y., Winn, R.A., Jemal, A., Siegel, R.L. (2022). Cancer statistics for African American/Black people 2022. *CA Cancer J Clin*; 72(3): 202-229.
6. Islami, F., Guerra, C.E., Minihan, A., Yabroff, K.R., Fedewa, S.A., Sloan, K., et al. (2022). American Cancer Society's report on the status of cancer disparities in the United States, 2021. *CA Cancer J Clin*; 72: 112–143.
7. National Alliance for Caregiving & AARP. (2020) Caregiving in the United States 2020 Report. Available at: <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>.
8. Hunt, G.H., Longacre, M. L., Kent, E. E., Weber-Raley, L. (2016) Cancer caregiving in the U.S.: An intense, episodic, and challenging care experience. National Alliance for Caregiving. Available at: https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf.
9. Fabius, C.D., Wolff, J.L., Kasper, J.D. (2020). Race Differences in characteristics and experiences of black and white caregivers of older americans. *Gerontologist*; 60 (7): 1244–1253.
10. Longacre, M.L., Miller, M.F., Fang, C.Y.. (2021). Racial and ethnic variations in caregiving-related physical, emotional, and financial strain during COVID-19 among those caring for adult cancer patients. *Support Care Cancer*; 29(7): 4137-4146.
11. Longacre, M.L., Ridge, J.A., Burtness, B.A., Galloway, T.J., Fang, C.Y. Psychological functioning of caregivers for head and neck cancer patients. (2012). *Oral Oncology*; 48(1): 18-25.
12. National Alliance for Caregiving and Caring Across Generations. (2019). Burning the candle at both ends: Sandwich generation caregiving in the U.S. Available at: https://www.caregiving.org/wp-content/uploads/2020/05/NAC-CAG_SandwichCaregiving_Report_Digital-Nov-26-2019.pdf.
13. Longacre, M. L., Brewer, B., Hubbard, A., Ashare, R. L., Patterson, F. (2021). Caregiver health by context: Moderating effects of mental health and health behaviors. *Western Journal of Nursing Research*; 43(7): 622-630.



References

14. Hopps, M., Iadecola, L., McDonald, M., Makinson, G. T. (2017). The burden of family caregiving in the United States: Work productivity, health care resource utilization, and mental health among employed adults. *Journal of Multidisciplinary Healthcare*; 10: 437–444.
15. Fang, C.Y., Galloway, T.G., Egleston, B.L., Bauman, J.R., Ebersole, B., Chwistek, M., Bühler, J.G., Longacre, M.L., Ridge, J.A., Manne, S.L., Manning, C. (2021). Development of a web-based supportive care program for patients with head and neck cancer. *Frontiers in Oncology*; 2020 Dec 15;10:602202.
16. Alzehr, A., Hulme, C., Spencer, A., Morgan-Trimmer, S. (2022). The economic impact of cancer diagnosis to individuals and their families: A systematic review. *Supportive Care in Cancer*; 30: 6385-6404.
17. de Moor, J.S., Williams, C.P., and Blinder, V.S. (2022). Cancer-related care costs and employment disruption: Recommendations to reduce patient economic burden as part of cancer care delivery. *J Natl Cancer Inst Monogr*; (59): 79-84.
18. Sherwood, P.R., Given, B.A., Donovan, H., Baum, A., Given, C.W., Bender, C.M., Schulz, S. (2008). Guiding research in family care: a new approach to oncology caregiving. *Psycho-oncology*; 17: 986–996
19. Litzelman K., Yabroff K.R. (2015). How are spousal depressed mood, distress, and quality of life associated with risk of depressed mood in cancer survivors? Longitudinal findings from a national sample. *Cancer Epidemiology Biomarkers and Prevention*; 24(6): 969-977.
20. Milbury K., Badr H., Fossella F., Pisters K.M., Carmack C.L. (2013). Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung cancer. *Supportive Care in Cancer*; 21(9): 2371 – 2379.
21. Van Houtven C.H., Voils C.I., Weinberger M. (2011). An organizing framework for informal caregiver interventions: detailing caregiving activities and caregiver and care recipient outcomes to optimize evaluation efforts. *BMC Geriatr*; 11:77.
22. Mittelman M.S., Ferris S.H., Steinberg G., et al. (1993). An intervention that delays institutionalization of Alzheimer's disease patients: treatment of spouse-caregivers. *Gerontologist* ;33(6): 730-740.
22. Mittelman M.S., Haley W.E., Clay O.J., Roth D.L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*; 67(9): 1592-1599.



References

23. IOM. Retooling for an aging America: Building the healthcare workforce. Washington, DC: The National Academies Press; 2008.
24. Alfano C.M., Leach C.R., Smith T.G., et al. (2019). Equitably Improving outcomes for cancer survivors and supporting caregivers: A blueprint for care delivery, research, education, and policy. *CA: A Cancer Journal for Clinicians*; 69(1): 35-49.
25. Wolff J.L., Feder J., Schulz R. (2016). Supporting family caregivers of older americans. *New England Journal of Medicine*; 375(26): 2513-2515.
26. Coleman E.A. (2016). Family Caregivers as partners in care transitions: The Caregiver Advise Record and Enable Act. *Journal of Hospital Medicine*; 11(12): 883-885.
27. Carman K.L., Dardess P., Maurer M.E., Workman T., Ganachari D., Pathak-Sen E.A. (2014). Roadmap for patient and family engagement in healthcare practice and research. The American Institutes for Research.
28. Frampton S.B., Guastello S., Hoy L., Naylor M., Sheridan S., Johnston-Fleece M. (2017) Harnessing evidence and experience to change culture: A guiding framework for patient and family engaged care. National Academy of Medicine.
29. Longacre M.L., Keleher C., Chwistek M., et al. (2021). Developing an Integrated Caregiver Patient-Portal System. *Healthcare*; 9(2).
30. Longacre M.L., Chwistek M., Collins M., et al. (2021). Palliative care clinicians' perspectives of an integrated caregiver patient-portal system in oncology. *Cancer Care Research Online*; 1(4).
31. Mackwood, M.B., Butcher, R.L., Vaclavik, D. Alford-Teaster, J.A., Curtis, K.M., Lowry, M.L., Tosteson, T.D., Zhao, W., & Tosteson, A.N. (2022) Adoption of telemedicine in a rural United States cancer center amidst the COVID-19 pandemic: A qualitative study. *JMIR Cancer*; Jul 21. doi: 10.2196/33768.