

Remotely Delivered Evidence-Based Dementia Caregiving Programs in *Best Practice Caregiving*

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best practice
caregiving | Guiding organizations
to dementia programs
for family caregivers

A partnership between
Benjamin Rose Institute on Aging and Family Caregiver Alliance

Funded by The John A. Hartford Foundation, Archstone Foundation, and The Retirement Research Foundation

Collaborators:

Benjamin Rose Institute on Aging: Cleveland non-profit that conducts applied aging research and services to older adults and the caregivers.

Family Caregiver Alliance: San Francisco non-profit dedicated to promoting health and well-being of family/friend caregivers

The Gerontological Society of America: Washington D.C. interdisciplinary organization in the field of aging dedicated to research, education, and practice.

Funders :



The John A. Hartford Foundation
Dedicated to Improving the Care of Older Adults



RRF | Foundation
for Aging



Dementia Prevalence, Cost, and Care

- 5.8 million Americans have Alzheimer's disease; 5.6 million 65+
- Number will triple by 2050
- Medicare and Medicaid cost \$195 billion; 67% of total
- Family and friend caregivers provide 83% of care
- 18.5 billion hours of care, valued at \$234 billion

Alzheimer's Association. (2019). Alzheimer's Disease Facts and Figures. Retrieved from:

<https://www.alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf>

Alzheimer's Association. (2019). Cost of Alzheimer's to Medicare and Medicaid. Retrieved from:

http://act.alz.org/site/DocServer/2012_Costs_Fact_Sheet_version_2.pdf?docID=7161

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Caregiving for Persons with Dementia

15 million US family/friend caregivers

Caregivers of persons living with dementia:

- More adverse caregiving consequences (e.g., isolation, relationship strain, depression)
- Assist with more tasks and more difficult tasks
- Deal with more stressful symptoms (e.g., behavioral symptoms)
- Person living with dementia may have limited ability for self-care

Major Advance in Caregiving

Many non-pharmacological programs with proven benefits for family/friend caregivers.

Some programs also have proven benefits for persons living with dementia.

National Academies of Sciences, Engineering, and Medicine, Committee on Family Caregiving for Older Adults, Board on Health Care Services, Health and Medicine Division (2016). Schulz R. and Eden J., editors. Families Caring for an Aging America. Washington (DC): National Academies Press (US).

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The Problem - Limited Program Availability & Use

Despite proven benefits:

- Few programs are widely available from healthcare and community service organizations
- Most healthcare and community service organizations offer none of these programs
- Most family and friend caregivers do not have access and/or do not use any of these proven programs

One Reason for Low Availability and Use

Most professionals have limited knowledge of these evidence-based programs

No comprehensive, updated information source

- Limited information in published articles –
Particularly about implementation experiences and delivery tools
- Difficult to know which programs are:
 - Best match for a particular organization or community
 - Ready for non-research community implementation
 - Being delivered and working well in other communities

Maslow, K. (2012). *Translating innovation to impact: Evidence-based interventions to support people with Alzheimer's disease and their caregivers at home and in the community*. Administration on Aging and Alliance for Aging Research.

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***Best Practice Caregiving* – Phase I Version**

Easy-to-use online tool for professionals

Launched January 2020

44 evidence-based dementia caregiving programs

- Comprehensive program profiles
- Detailed information on implementation features
- Experiences of non-research delivery sites
- Key features from evidence-based research
- Complete program bibliographies
- Contact information for program developers or distributors

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Professionals Who Will Use Best Practice Caregiving

Primary Audiences:

- Healthcare Associations
- Hospital & Healthcare Systems
- Government Departments on Aging and Health
- Community Service Organizations
- Alzheimer's & Dementia Specific Organizations

Other Audiences:

- Federal Agencies
- Policy Associations
- Foundations and Interested Private Donors
- Learning Collaboratives
- Advocates for Caregivers and Persons with Dementia

Program Eligibility Criteria

1. At least 1 completed US randomized controlled trial, non-randomized controlled trial, or pre-post-test without control group
 - At least 50% sample caregivers of persons living with dementia in the community
 - At least one statistically significant, published, beneficial caregiver outcome
2. At least 1 other implementation where program was offered as a regular service
3. Availability of: permission/license to deliver the program, manuals, training, and delivery tools

Finding Eligible Programs

- Started in 2017 pilot project and 50 known possible programs
- Searched published systematic reviews; online literature searches; conference presentations; grants from ACL, NIH, and VA; and presentations is LEAD and NAPA
- Recommendations from the Advisory Committee, funders, researchers, clinicians, and service providers
- **We missed some eligible programs and will be adding more throughout 2021**

Guiding Principles - Best Practice Caregiving

- Inclusive definition of “Evidence-Based”
- Provide detailed information; not subjective ratings
- Emphasize implementation characteristics and experiences of delivery sites - Basics about the research
- All the information needed to take the next step toward program implementation
- Identify gaps for new program development

ACCESS	EPIC	REACH VA
ACES	Home Safety Toolkit	Savvy Caregiver
Adult Day Services Plus (ADSP)	Inner Resources for Stress	Scott & White Family Caregiver Program
African-American Alzheimer's Training and Caregiver Support (ACTS-2)	Memory Club	SHARE
ANSWERS	Mindfulness-Based Alzheimer's Caregiving Program	Skills2Care
At the Crossroads	Mindfulness-Based Dementia Care	STAR-C
Behavioral Treatment of Insomnia for Caregivers	Mindfulness-Based Stress Reduction for Caregivers of Frail Elderly	Stress-Busting Program
BRI Care Consultation	Mindfulness-Based Stress Reduction for Dementia Caregivers	SUSTAIN
Building Better Caregivers	Minds in Motion	Tailored Activities Program (TAP)
CALMA: Reach to Caregivers	Mindfulness Training for Patients with Progressive Cognitive Decline and their Caregivers program	TCARE®
CarePRO	New York University Caregiver Intervention (NYUCI)	Telenovela Mirela
Central Texas Community Living Program	Powerful Tools for Caregivers	The Unforgettables
Collaborative Care	RCI REACH	Together We Can! Facing Memory Loss as a Family
COPE	Reducing Disability in Alzheimer's Disease (RDAD)	UCLA Alzheimer's and Dementia Care
Dealing with Dementia	REACH Community	Yogic Meditation

Types of Assistance Programs Provide

- Caregiver-PWD Communication
- Coping
- Healthy Behaviors
- Positive Caregiver-PWD Activities
- Symptoms of Dementia
- Stigma or Isolation
- Daily Tasks
- Preventing Emergencies & Harm
- Assessment of Problems
- End-of-Life Support
- Care Transitions
- Advanced Directives
- Finances
- Coordinating Home & Family Care
- Accessing Medical Care
- Coordinating Medical Care
- Pain Management
- Dementia Diagnosis
- Ongoing Monitoring of Services

Best Practice Caregiving Program Delivery Sites

324 US healthcare or community service organizations deliver 1 or more programs

- 350 program offerings
- Most common delivery sites:
 - 24% healthcare organizations
 - 24% Area Agencies on Aging
 - 12% Alzheimer's or Dementia community organization
- Most common funding sources - 54% Titles III-B, D, E of the Older Americans Act; 39% grants
- Programs implemented for diverse populations
 - 4 Developed for Hispanic/Latinx Caregivers
 - 1 Developed for African American Caregivers
 - 17 Adapted or language translations

Remotely Delivered Programs (Telephone, Online, Recorded)

- Increasingly common before Covid-19
- Some originally remote, others being adapted
- More convenient for busy/working caregivers, do not have to leave care receiver
- Overcomes transportation and geographic barriers
- Telephone an effective option
- Increasing familiarity with online tools
- Serve more families at a lower cost

12 Remotely Delivered Programs

- Mode of Delivery
 - 7 By telephone
 - 5 Online
 - 1 Print
- Length
 - 2 Ongoing services
 - 8 Time limited, multiple education/training sessions
 - 2 Time limited, self-administered
- Diverse Caregivers
 - 3 Developed for diverse populations
 - 4 Adapted or translated

12 Remotely Delivery Programs in [Best Practice Caregiving \(bpc.caregiver.org\)](http://bpc.caregiver.org)

Program Name	Brief Description	Developer
Active Caregiving: Empowering Skills (ACES)	4 in-person or telephone , group education and skills-training sessions for caregivers, focused on stress management, pleasant events, and strategies for reducing behavioral symptoms. Active Caregiving: Empowering Skills (ACES)	Gallagher-Thompson
African American Alzheimer's Caregiver Training and Support Project 2 (ACTS-2)	12 telephone sessions for African American caregivers of persons with dementia, focusing on skills-building, spiritual support, and improving self-care and the relationship with the person living with dementia. African-American Alzheimer's Caregiver Training and Support Project 2 (ACTS-2)	Glueckauf
BRI Care Consultation™	Ongoing telephone, optional email , individual care-coaching for caregivers and persons living with dementia and/or other chronic conditions, focused on accessing community and family resources, quality information, and emotional support. BRI Care Consultation™	Bass
Building Better Caregivers Online Mode	12 to 18 online , group education sessions for caregivers, focused on techniques for reducing stress, action planning, problem-solving, and decision-making. Building Better Caregivers Online Mode	Lorig
Inner Resources for Stress	8 in-person or online , group education sessions for caregivers of persons living with dementia and/or other chronic conditions on mindfulness, meditation, and breath-focused mantra repetition, focused on stress management and resiliency. Inner Resources for Stress	Waelde

Program Name	Brief Description	Developer
REACH Community (Resources for Enhancing Alzheimer's Caregivers in the Community)	4 in-person or telephone , individual education and skills- training sessions for caregivers, focused on care planning, understanding the injury or illness of the person needing care, problem-solving, and stress management. REACH Community (Resources for Enhancing Alzheimer's Caregivers in the Community)	Martindale-Adams & Nichols
REACH VA (Resources for Enhancing All Caregivers Health in the VA)	4 in-person or telephone , individual education and skills- training sessions for caregivers of veterans living with dementia, focused on care planning, understanding the injury or illness of the person needing assistance, problem-solving, and stress management. REACH VA (Resources for Enhancing All Caregivers Health in the VA)	Nichols & Martindale-Adams
Savvy Caregiver	6 in-person or online , group education and skills-training sessions for caregivers, focused on enhancing caregiving knowledge and skills, coping with stress, and encouraging persons living with dementia to participate in daily tasks and activities. Savvy Caregiver	Hepburn
TCARE (Tailored Caregiver Assessment and Referral)	Ongoing in-person or telephone , individual care-management and support program for caregivers of persons living with dementia and/or other chronic conditions, focused on assessment, care planning, and accessing community resources. TCARE (Tailored Caregiver Assessment and Referral)	Montgomery
Telehealth Education Program for Caregivers of Individuals with Dementia	10 telephone , individual education sessions for caregivers of persons living with dementia, focused on basics on dementia, behavioral symptoms, communication, future planning, and coping. Telehealth Education Program for Caregivers of Individuals with Dementia	Wray, Toseland, et. al
Telenovela Mirela	Video package for Hispanic/Latino caregivers of persons living with dementia, focused on coping with caregiving. Telenovela Mirela	Photozig, Inc.
Together We Can!	Community teaching guide , in English and Spanish for Hispanic/Latino caregivers, focused on providing quality care, caregiver coping and support, and community resources. Together We Can!	Gallagher-Thompson

Best Practice Caregiving: Next Steps and Phase II

Marketing to increase knowledge, use, and delivery of programs

Implement sustainability business plan – Offer organizational sponsorships; Consultation on program selection and delivery

Add eligible programs in 2021 (9 to 12 more in the cue)

Disseminate results from Best Practice Caregiving:

- “Characteristics and Experiences of Organizations Delivering Evidence-Based Dementia Caregiving Programs”
- “Strengths and Gaps in Evidence-Based Dementia Caregiving Programs”

Seek funding for Phase II of Best Practice Caregiving:

- Create version for caregivers, families, and consumers to find dementia caregiving programs in their communities
- More programs for diverse caregivers

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Visit **Best Practice Caregiving** at

bpc.caregiver.org

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