

Finding the Right Dementia Caregiving Program: A Guided Tour of *Best Practice Caregiving*

Wednesday, February 5, 2020

Webinar will begin at 10 a.m. (Pacific) / 1 p.m. (Eastern)

best practice
caregiving

*Guiding organizations
to dementia programs
for family caregivers*

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

Agenda

- ▶ Background and context for *Best Practice Caregiving*
- ▶ Overview of the database and programs
- ▶ Live demo of the site
- ▶ Q&A

Today's Presenters



Rani Snyder, MPA, Vice President, Program
The John A. Hartford Foundation



David Bass, PhD, Senior Vice President
Benjamin Rose Institute on Aging,
Center for Research and Education



Kathy Kelly, MPA, Executive Director
Family Caregiving Alliance: *National Center
on Caregiving*

Background and Context



Rani Snyder, MPA, Vice President, Program
The John A. Hartford Foundation

Our Generous Project Funders Include



The John A. Hartford Foundation

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Overview of the Database and Programs



David Bass, PhD, Senior Vice President
Benjamin Rose Institute on Aging,
Center for Research and Education

Project Development Team

David M. Bass, PhD

Principal Investigator

Benjamin Rose Institute on Aging, Center for Research & Education

Kathleen Kelly, MPA

Co-Principal Investigator

Family Caregiver Alliance: National Center on Caregiving

Katie Maslow, MSW

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Gerontological Society of America

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Family Caregiver Alliance: National Center on Caregiving

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Program Specialist

Family Caregiver Alliance: National Center on Caregiving

Rachel Schaffer, MPH

Research Analyst

Benjamin Rose Institute on Aging, Center for Research & Education

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Advisory Committee

Troy Andersen

The University of Utah School of Medicine

Salli Bollin

Alzheimer's and Dementia Care Services of Northwest Ohio

Debra Cherry

Alzheimer's Greater Los Angeles

Leisa Easom

College of Nursing and Health Sciences, Georgia Southwestern State University

Laura Gitlin

Drexel University

Lisa Gwyther

Duke University

Joan Hatem-Roy

Elder Services of Merrimack Valley

Heather Hodge

YMCA of the USA

Meg Kabat

Atlas Research

Lynne Korte

Washington State Department of Social and Health Services

Erin Long

Administration for Community Living, US Department of Health and Human Services

Jennifer Martindale-Adams

Caregiver Center at the Memphis VA Medical Center
University of Tennessee Health Science Center

Diane Meier

Center to Advance Palliative Care

Alan Stevens

Center for Applied Health Research, Baylor Scott & White

Jane Tilly (Retired)

Administration for Community Living, US Department of Health and Human Services

Laura Trejo

City of Los Angeles Department on Aging

Donna Walberg

RTI International

Nancy Wilson

Baylor College of Medicine
Michael E. DeBakey Veterans Affairs Medical Center

Carol Zernial

WellMed Medical Management, Inc.

Builds upon a Major Advance in Caregiving

- ▶ Development and testing of many non-pharmacological programs that have proven benefits for family or friend caregivers
- ▶ Some programs also have proven benefits for persons living with dementia
- ▶ Some programs are ready for broad scale community implementation

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).

Examples of Assistance Programs Offer

▶ Assessing and/or managing symptoms and caregiving	▶ Managing daily tasks and activities
▶ Accessing or monitoring medical care	▶ Providing end-of-life care
▶ Understanding symptoms, diagnosis, and/or prognosis	▶ Involving and coordinating help from family and friends
▶ Planning for care	▶ Finding, accessing and coordinating services
▶ Communicating effectively with persons with dementia	▶ Dealing with transitions in care and caregiving
▶ Dealing with legal and/or financial issues	▶ Relationship between caregiver and person receiving care
▶ Coping with illness and/or caregiving	▶ Maintaining health and wellness

Program Availability

- ▶ Despite proven benefits, most proven programs are not currently offered by healthcare and community organizations
- ▶ Most are not available to families
- ▶ **Problem** — Many professionals do not know about these programs
 - No easy-to-use comprehensive, updated information source
 - Limited and/or difficult to find information in published articles on implementation characteristics
 - ✓ Manuals
 - ✓ Characteristics of delivery staff
 - ✓ Training for delivery staff
 - ✓ Costs to deliver

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.

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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Best Practice Caregiving — **Part of the Solution**

- ▶ Easy-to-use online tool for professionals
- ▶ 42 proven dementia caregiving programs
- ▶ For each program it includes:
 - ✓ Comprehensive program profile
 - ✓ Detail on implementation features
 - ✓ Experiences of current delivery sites
 - ✓ Overview of research studies and findings
 - ✓ Complete program bibliographies
 - ✓ Contact information for developers or distributors

Best Practice Caregiving — Program Eligibility

- ▶ Completed randomized or non-randomized controlled trial, or pre/post-test study with no control group
 - ✓ Sample with at least 50% dementia caregivers
 - ✓ Conducted in U.S.
 - ✓ At least 1 statistically significant, published, beneficial caregiver outcome
- ▶ 1 or more implementations as part of an organization's regular service portfolio
- ▶ Availability of permission/license to offer the program and required delivery tools (e.g., manuals, training, record keeping systems)

Best Practice Caregiving — **Guiding Principles**

- ▶ Inclusive definition of “Evidence-Based”
- ▶ Detailed information; not subjective ratings
- ▶ Focus on:
 - ✓ Program and implementation characteristics
 - ✓ Experiences of delivery sites
 - ✓ Basics about the research (e.g., design, outcomes)
 - ✓ All information to take the next steps toward adoption
- ▶ Must be updated and sustainable
- ▶ Identify gaps to guide new program development

Methodology for Program Profiling



42 Programs for Dementia Caregivers

1. Active Caregiving: Empowerment Skills (ACES)
2. Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS)
3. Adult Day Services Plus (ADS PLUS)
4. African-American Alzheimer's Training and Caregiver Support (ACTS-2)
5. Aging Brain Center (Collaborative Care)
6. Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS)
7. At the Crossroads
8. Behavioral Treatment of Insomnia for Caregivers
9. BRI Care Consultation
10. Building Better Caregivers
11. Building Better Caregivers Online
12. CALMA: Reach to Caregivers
13. Care of Persons with Dementia in their Environments (COPE)
14. Care Partners Reaching Out (CarePRO)
15. Early-Stage Partners in Care (EPIC)
16. Inner Resources for Stress
17. The Memory Club
18. Mindfulness Training for Patients with Progressive Cognitive Decline and their Caregivers
19. Mindfulness-Based Alzheimer's Caregiving
20. Mindfulness-Based Dementia Care
21. Mindfulness-Based Stress Reduction for Dementia Caregivers
22. Minds in Motion
23. New York University Caregiver Intervention (NYUCI)
24. Powerful Tools for Caregivers
25. RCI REACH
26. Reducing Disability in Alzheimer's Disease (RDAD)
27. REACH Community
28. REACH VA
29. Savvy Caregiver
30. Scott & White Family Caregiver Program (REACH TX)
31. Skills2Care®
32. STAR Caregiver (STAR-C)
33. Stress-Busting Program for Family Caregivers
34. Support Health Activities Resources Education (SHARE)
35. Telehealth Education Program for Caregivers of Veterans with Dementia (SUSTAIN)
36. New Ways for Better Days: Tailoring Activities for Persons with Dementia and Caregivers (TAP)
37. Tailored Caregiver Assessment and Referral (TCARE)
38. Telenovela Mirela
39. The Unforgettables
40. Together We Can!
41. UCLA Alzheimer's and Dementia Care (UCLA ADC)
42. Yogic Meditation

Next Steps for *Best Practice Caregiving*

- ▶ Beginning a two-year dissemination grant
 - ✓ Implement marketing and dissemination campaign
 - ✓ Update program profiles
 - ✓ Add newly identified and newly eligible programs
 - ✓ Implement a financial sustainability plan
 - ✓ Evaluate impact and refine content
- ▶ Explore possible expansions
 - ✓ Develop a consumer version
 - ✓ Expand focus areas (e.g., non-U.S. program, programs only for persons with dementia, programs for non-dementia caregivers)

Live Demo of *Best Practice Caregiving*



Kathy Kelly, MPA, Executive Director
Family Caregiving Alliance: *National Center
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Home Find Programs

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Dementia Care Programs

Best Practice Caregiving is a free online database of proven dementia programs for family caregivers. It offers a searchable, interactive, national database of vetted, effective programs that offer much-needed information and support. The database is an invaluable tool for healthcare and community-based organizations, as well as funders and policy makers to discover and share high quality programs for caregivers.

In the Best Practice database you will find detailed information about:

- focus of each program (e.g., reducing stress, understanding dementia, planning care, skill-building, health & wellness, etc.)
- program implementation
- research findings
- direct utilization experiences of delivery sites
- program developer information.

[Click Here for Programs ▶](#)

How to Use the Database

With more than 40 data records, you'll have access to the information you need to make informed decisions. It's easy to compare programs side-by-side based on the factors that matter most to you, your organization, and your caregiving clients. Contact and usage/license fee information are included for each program.

[Learn More ▶](#)

FCA CareJourney

Thank you!

... to our presenters:

David Bass, Senior Vice President, Benjamin Rose Institute on Aging, dbass@benrose.org

Kathy Kelly, Executive Director, Family Caregiver Alliance, kkelly@caregiver.org

Rani Snyder, Vice President, The John A. Hartford Foundation, rani.snyder@johnahartford.org

... our developers:

Benjamin Rose Institute on Aging, Center for Research and Education benrose.org

Family Caregiver Alliance: *National Center on Caregiving* caregiver.org

The Gerontological Society of America geron.org

... and our funders:

The John A. Hartford Foundation johnahartford.org

Archstone Foundation archstone.org

RRF Foundation for Aging rrf.org

Get Updates

Sign up for
updates and news on *Best Practice Caregiving* at:

BestPracticeCaregiving@caregiver.org

Visit the database at: bpc.caregiver.org

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