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)
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
Dedicated to Improving the Care of Older Adults

RRF | Foundation for Aging

best practice caregiving
Guiding organizations to dementia programs for family caregivers

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

1. Benjamin Rose Institute on Aging
2. Family Caregiver Alliance
3. THE GERONTOLOGICAL SOCIETY OF AMERICA
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

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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.
Overview of the Database and Programs

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

### 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


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)
Overview of the Database and Programs

**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

1. Developer and Distributor Survey
2. Manuals Review
3. Delivery Site Survey
4. Studies Review
Overview of the Database and Programs

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)
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 on Caregiving
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 ➤
Thank you!

... to our presenters:
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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:
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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**