

best practice caregiving

*Guiding organizations
to dementia programs
for family caregivers*

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

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COLLABORATING ORGANIZATIONS

Benjamin Rose Institute on Aging, Center for Research and Education — A Cleveland-based nonprofit, founded in 1908, whose mission is to advance support for older adults and caregivers. *(Bass, Ciancibello, Rentsch, and Schaffer)*

Family Caregiver Alliance / National Center on Caregiving — A San Francisco-based non-profit celebrating 40+ years dedicated to the health and well-being of family caregivers through information, education, support, and research. *(Kelly and Eskenazi)*

GSA Visiting Scholar — *(Maslow)*

PROJECT FUNDERS



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

Jane Carmody and Mary Jane Koran, Program Officers



Laura Rath, Program Officer

THE
RETIREMENT
RESEARCH
FOUNDATION

Nancy Zweibel, Program Officer



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FAMILY AND FRIEND CAREGIVERS

- ✓ 8.5 million U.S. family/friend caregivers
- ✓ Dementia caregivers more adverse effects
- ✓ Assist with more and more difficult tasks
- ✓ Deal with stressful symptoms
- ✓ Person's ability for self-care is limited and worsens over time



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PROGRAMS THAT SUPPORT FAMILY AND FRIEND CAREGIVERS

A major advance has been the development and testing of programs that support family/friend caregivers and, in some cases, the person living with dementia.

The Challenge:

- ✓ Few programs are available in most communities
- ✓ Most programs are not being delivered by health and social organizations
- ✓ Most programs are not accessible to families

ONE REASON PROGRAMS ARE NOT AVAILABLE

No comprehensive source with detailed information about proven programs

- ✓ Limited information in published articles — Particularly about implementation experiences and delivery tools
- ✓ Lack of easy-to-find, detailed program descriptions to know:
 - The best match for an organization or community
 - Which ones are available and ready for community delivery
 - Which ones have worked well in other communities

best practice caregiving — PART OF THE SOLUTION

Goal: Increase program availability for families by giving organizations and professionals easy access to:

- ✓ Comprehensive program profiles
- ✓ Basics about research findings
- ✓ Detailed information about implementation features
- ✓ Information about experiences of existing delivery sites
- ✓ Designed for healthcare and social service organizations, providers, and funders



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GUIDING PRINCIPLES

- ✓ Inclusive definition of “Evidence-Based”
- ✓ Detailed information; not subjective ratings
- ✓ All the information needed to take the next step toward implementation of a new program
- ✓ Identify gaps in existing programs; inform new program development
- ✓ Provide sustained, updated information



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PROGRAM ELIGIBILITY

1. At least 1 completed, U.S.-based, study that:
 - was a randomized controlled trial, non-randomized controlled trial, or pre-test post-test without a control group
 - had at least 50% of the sample comprised of family/friend caregivers assisting a person living with dementia in the community.
 - at least one statistically significant, published, beneficial outcome for caregivers.
2. At least 1 other implementation where the program was:
 - delivered by a health or social service organization or provider as a regular service.
 - used by at least some family/friend caregivers assisting a person living with dementia living in the community.
3. Permission and/or license to deliver the program is available, along with manuals, training, and any other delivery tools.



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CURRENT PROGRAM LIST

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



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PROGRAM PROFILING METHODOLOGY



DEVELOPER SURVEY

DEVELOPER SURVEY

Program description and conceptual framework

Languages program is available

Applicability to other chronic conditions

Types of organization that delivers program

Discipline and experience of qualified delivery persons

Strategies for financial support of program

Program delivery costs: training, licensing, recordkeeping systems, manuals, marketing

Changes made from original program

Training for delivery staff: length, method, frequency

Assistance program provides

How assistance is provided: direct assistance, skills training, providing information, referring

Expected outcomes

Who to contact for more information



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MANUALS REVIEW

Assistance program provides

Description of sessions and contacts

Languages program is available

Applicability to other chronic conditions

Discipline & experience of qualified delivery persons

Target populations to receive program

Characteristics of manuals

Characteristics of recordkeeping systems

Licensing agreements

Required organizational resources: staffing, supplies, space, equipment, marketing

ARTICLES REVIEW

Study design

Sample size and eligibility

Study sites

Data collection methods

Outcomes and impacts

Bibliography of Published Articles



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#	%	FUNDING SOURCES INDICATED BY DEVELOPERS AND DELIVERY SITES
23	74%	Grants other than ACL
19	61%	Organization Operating Funds
17	55%	Donations or Fees
16	52%	ACL State Grants: Alzheimer’s Disease and Supportive Services
16	52%	State Funding
13	42%	Title III-D (OAA Health Promotion and Disease Prevention)
8	26%	Medicaid
8	26%	Title III-E (OAA National Family Caregiver Support)
7	23%	Title III-B (OAA Supportive Services)
6	19%	Local Government
6	19%	Medicare
4	13%	United Way Funds
2	6%	Employer Benefits / Assistance Program
1	3%	Private Insurance



15 TYPES OF ASSISTANCE

- ✓ Assessing Symptoms and Care
- ✓ Coordinate/Monitor Services
- ✓ Coping with Illness/Caregiving
- ✓ Daily Tasks
- ✓ Diagnosis or Prognosis
- ✓ Effective Communication
- ✓ End-of-Life Care
- ✓ Finances
- ✓ Health and Wellness
- ✓ Involving Family/Friends
- ✓ Managing/Understanding Symptoms
- ✓ Medical Care
- ✓ Planning for Care
- ✓ Relationship of Dyad
- ✓ Transitions in Care



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MOST AND LEAST COMMON TYPES OF ASSISTANCE PROVIDED

MOST COMMON: Managing and Understanding Symptoms

Health and Wellness

Coping with Illness/Caregiving

Relationship of Dyad

LEAST COMMON: Finances

End-of Life Care

Coordinate/Monitor Services



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DELIVERY SITE: ORGANIZATION TYPE

#	%	NUMBER OF DELIVERY SITES = 221
68	29%	Area Agency on Aging
58	26%	Health System
56	25%	Alzheimer's Association Chapter or Dementia Support Organization
39	18%	Senior Center or Meals Program
31	13%	Family Caregiving Organization
27	12%	Adult Day Program
24	11%	Long-Term Care Facility
19	9%	Therapy Organization
17	8%	Recreational Organization
16	7%	Senior Housing Facility
9	4%	Home Health Organization
9	4%	Independent Service Provider
9	4%	Faith-Based Organization
2	1%	Developmental/Intellectual Disabilities Organization
21	10%	Other



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FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

THANK YOU!

Please feel free to email me if you have or know of a program we should consider for the *Best Practice Caregiving* database.

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DATABASE DESIGN

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Family Caregiver Alliance

PATHWAYS TO DATABASE ENGAGEMENT

Leah Eskenazi
Family Caregiver Alliance



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WHO WILL USE?

PRIMARY:

Hospital and Healthcare Systems
Health Care Associations
State Departments on Aging and Health
Large Community Based Social Service Organizations
Alzheimer's and Dementia Specific Organizations

SECONDARY:

Federal Agencies
Policy Associations
Foundations and Interested Private Donors
Researchers and Academic Professionals and Organizations
Learning Collaboratives
Advocates for Caregivers and Individuals living with Dementia



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USE THIS DATABASE AND YOU WILL BE EVEN SMARTER ...

- ✓ Are vetted with documented outcomes — evidence and practice-based
- ✓ Offer direct experience as a service delivered to a family/friend/partner caring for an individual living with dementia
- ✓ Are published and included in a comprehensive literature review covering all programs in this database
- ✓ Offer implementation materials for program adoption and delivery



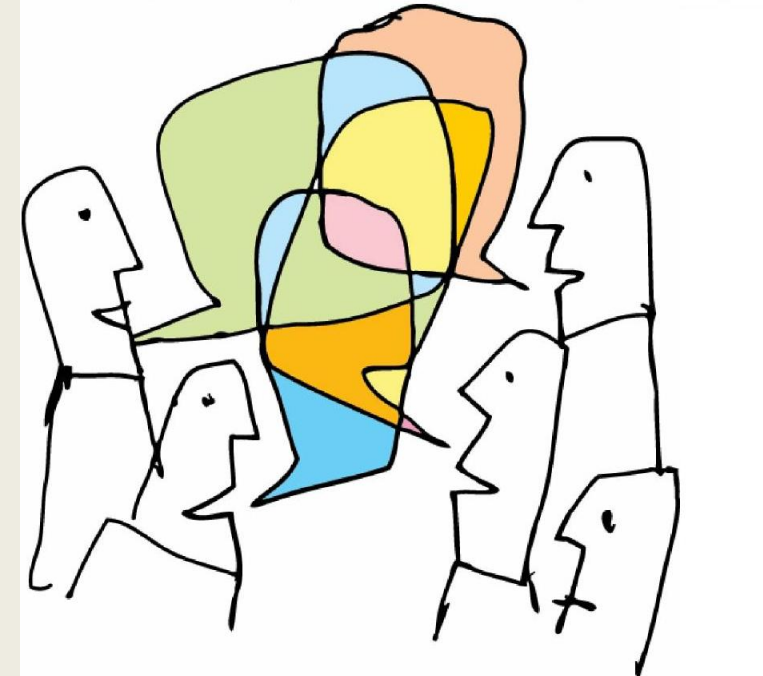
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WHAT CAN YOU DO?

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A comprehensive and interactive online resource for Best Practice Dementia Caregiving Programs



➔ Join us to **Beta Test**.

➔ **Send Contact Info:** yours — and any others who need to know — to receive the official *Best Practice Caregiving* launch announcement!



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THANK YOU! & QUESTIONS?



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