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***Best Practice Caregiving: Guiding Organizations
 Dementia Programs for Family Caregivers***

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Project Team

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Funders

**The John A. Hartford
 Foundation**

Archstone Foundation

**The Retirement Research
 Foundation**

- Online tool on Family Caregiver Alliance Website
- Public launch November 2019
- Goal: To increase knowledge and adoption of non-pharmacological, evidence-based programs for family and friend caregivers by healthcare and community service organizations

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

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Supported by The Laura & John Arnold Foundation, Alzheimer's Association, and The Robert Wood Johnson Foundation

Limited 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 Caregiver Health Care Services, Health and Medicine Division (2016). Schulz, R. and Eden J., editors. *Best practice caregiving: Guiding organizations to dementia programs for family caregivers*. 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
 - ✓ Characteristics of and findings from research studies
 - ✓ Complete program bibliographies
 - ✓ Contact information for developers or distributors

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Best Practice Caregiving – Program Eligibility

- 1 or more 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 US
 - ✓ At least 1 statistically significant, published, beneficial caregiver outcome
- 1 or more implementation that delivered the program 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)

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Guiding Principles - *Best Practice Caregiving*

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

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Methodology for Program Profiling



42 Programs for Dementia Caregivers

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



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 health and social service organizations to discover and share high quality caregiver programs with their clients and patients.

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.

[Find 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 ▶](#)

Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS)

by Katherine S. Judge, PhD

[Compare \(up to 3\)](#)

8 in-person, individual education and skills-training sessions for caregivers and persons living with dementia, focused on practical coping strategies and managing symptoms based on cognitive rehabilitation principles.

Delivery Person	Professional or paraprofessional
One-on-one Format	8 in-person sessions for caregivers and persons with dementia
Languages	English
Session Length	1.5 hours
Program Length	1.5 months

[Learn More](#)

Active Caregiving: Empowering Skills (ACES)

by Dolores Gallagher-Thompson, PhD

[Compare \(up to 3\)](#)

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.

Delivery Person	Trained lay leader, Professional or paraprofessional
Group Format	4 in-person or telephone sessions for caregivers
Languages	English, Spanish, Vietnamese
Session Length	2 hours
Program Length	1 month

[Learn More](#)

Adult Day Services Plus (ADS Plus)

by Laura N. Gitlin, PhD

[Compare \(up to 3\)](#)

Up to 8 in-person, individual skills-training and education sessions for caregivers and monthly check-ins, focused on assisting with caregiver-identified areas of concern, caregiver self-care and coping, and linking to community resources.

Delivery Person	Professional or paraprofessional
One-on-one Format	Up to 8 in-person sessions for caregivers
Languages	English
Session Length	Not available
Program Length	12 months

[Learn More](#)

Active Caregiving: Empowering Skills (ACES)



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[Program Information](#) | [Survey of Delivery Sites](#) | [Research Evidence](#)

Program Information	^
Program Overview	+/-
Program Components	+/-
Program Characteristics	+/-
Survey of Delivery Sites	^
Delivery Site Survey Information	+/-
Organization and Program Information	+/-
Research Evidence	^
Program Impact and Outcomes	+/-
Study Findings	+/-
Study Characteristics	+/-

Guiding organizations
by dementia programs
for family caregivers

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For More Information

Developers
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Contacts
Branka Primetica
11890 Fairhill Road, Cleveland, OH 44120
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216-373-1862
www.beyond.org
Provides: Manuals, Training, Other Resources

Program Articles

- Outcomes for patients with dementia from the Cleveland Alzheimer's managed care demonstration.
- Outcomes for patients with dementia from the Cleveland Alzheimer's managed care demonstration.
- The Cleveland Alzheimer's managed care demonstration: outcomes after 12 months of implementation.
- Findings from a real-world translation study of the evidence-based "Partners in Dementia Care."
- Caregiver outcomes of Partners in Dementia Care: effect of a care coordination program for veterans with dementia and their family members and friends.
- A controlled trial of Partners in Dementia Care: Veteran outcomes after six and twelve months.
- A break-even analysis for dementia care collaboration: Partners in Dementia Care.
- Impact of the care coordination program "Partners in Dementia Care" on veterans' hospital admissions and emergency department visits.
- Partners in Dementia Care: a care coordination intervention for individuals with dementia and their family caregivers.
- Reflections on implementing the evidence-based BRI Care Consultation with RCI in Georgia.

BRI Care Consultation

Ongoing telephone and email, individual care-coaching for caregivers and persons living with dementia and/or other chronic conditions, focused on assessing community and family resources, quality information, and emotional support.

Delivery Person	Professional or paraprofessional
One-on-one Format	Ongoing telephone sessions and email for caregivers and/or persons with dementia
Languages	English
Session Length	Not available
Program Length	Minimum of 3 months

[Program Information](#) [Survey of Delivery Sites](#) [Research Evidence](#)

Program Information

Program Overview

Target Populations

Types of dementia
All types of dementia

Other chronic conditions
List of other chronic conditions
Adults with a chronic physical, mental, or cognitive health condition or disability (e.g. arthritis, diabetes, cancer, depression, anxiety, physical frailty, developmental disabilities)

Program Costs

Cost or fee to obtain license
Yes

Base or certification cost
\$10,200

Included in cost
License/certification to deliver the program

Number of delivery persons included in cost
3

Length in years of license or certification
1

Renewal cost
\$3,300

Types of assistance program provides:	Provided to:	Direct Assistance	Information	Training	Referring
— Assessing and Monitoring Dementia Symptoms, Care, and/or Caregiving	PWD,CG	✓	✓		✓
Conducting an Initial Assessment for Dementia-Related Problems or Cognitive Impairment	PWD,CG	✓	✓		✓
Conducting a Reassessment of Dementia-Related Problems	PWD,CG	✓			
Getting or Conducting Medical Evaluations of Dementia	PWD,CG				✓
Monitoring the Benefits of Services and/or Treatments in Addition to the Program	PWD,CG	✓			
— Coordinating and/or Monitoring Care and Services *	PWD,CG	✓	✓		✓
Coordinating and Monitoring Medical Care	PWD,CG	✓	✓		✓
Coordinating and Monitoring Home and Community Services and Other Community Resources	PWD,CG	✓	✓		✓
Coordinating Medical Care and Home and Community Services	PWD,CG	✓	✓		✓
Coordinating and Monitoring Assistance from the Network of Family and Friends	PWD,CG	✓	✓		
+ Daily Tasks	PWD,CG		✓		✓
+ Diagnosis or Prognosis of Dementia	PWD,CG		✓		✓
+ End-of-Life Care	PWD,CG		✓		✓
+ Finances or Financial-Related Tasks	PWD,CG		✓		✓
+ Improving or Maintaining Health and Wellness	PWD,CG		✓		✓
+ Involving Family and Friends in Care *	PWD,CG	✓	✓		✓
+ Managing or Coping with Care and/or Caregiving *	PWD,CG	✓	✓		✓
+ Medical Care	PWD,CG		✓		✓
+ Planning for Current or Future Care *	PWD,CG	✓	✓	✓	✓
+ Relationship of Persons with Dementia and Caregiver	PWD,CG	✓	✓		✓
+ Skills for Communicating with Persons with Dementia	CG		✓		
+ Transitions in Where Care is Provided	PWD,CG		✓		✓
+ Understanding or Managing Symptoms of Dementia *	PWD,CG	✓	✓		✓

Program Characteristics	
Staffing	
Disciplines and degrees of delivery persons	
Social Work - Baccalaureate	
Social Work - Not Specified	
Nursing - Baccalaureate	
Nursing - Not Specified	
Other1 - Baccalaureate	
Other1 - Not Specified	
Other related fields	
Initial Training	
Initial training provided	
Yes	
Total time	
10 hours	
Number of sessions	
3 sessions	
Mode	
Telephone	
Webinar or online	
Procedures for demonstrating mastery	
Practice cases or mock cases	
Refresher Training	
Refresher training provided	
Yes	
Total time	
8 hours	
Number of sessions	
6 sessions year one, 2 sessions for subsequent years. Additional sessions as needed.	
Mode	
Telephone	
Webinar or Online	
Train-the-Trainer	
Train-the-trainer provided	
No	
Supervisor Training	
Supervisor training provided	

Survey of Delivery Sites	
Delivery Site Survey Information	
Number of eligible delivery sites surveyed	34
Number of completed delivery site surveys	20
Response rate	58.8%
Organization and Program Information	
Delivery History	
Average number of months site has delivered the program	31.7
Percent of sites that stopped delivering program in past 12 months	10%
Program User Characteristics	
Number of participants (average in past 12 months)	
All participants	145.1
Persons with a dementia diagnosis	32.7
Persons with memory problems without a dementia diagnosis	8.8
Persons with chronic illnesses or disabilities, other than dementia or memory problems	15
Family or friend caregivers of persons with a dementia diagnosis	63.7
Family or friend caregivers of persons with memory problems without a dementia diagnosis	16.5
Family or friend caregivers of persons with chronic illnesses or disabilities other than dementia or memory problems	8.3
Persons with dementia characteristics (average percent in past 12 months)	
Under 60 years of age	4%
Living in rural area	37%
Veteran	21%
Male	40%
Living alone	4%
Experiencing high levels of distress	27%
African-American	14%

Compare Evidence-based Programs

Search Programs

Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS)
 by Katherine S. Judge, PhD
 8 in-person, individual education and skills-training sessions for caregivers and persons living with dementia, focused on practical coping strategies and managing symptoms based on cognitive rehabilitation principles.
[See Program](#)

Support Health Activities Resources Education (SHARE)
 by Silvia Orsulic-Jeras
 5 in-person, individual care-planning sessions for caregivers and persons living with early-stage dementia, focused on managing symptoms, communications, and care values and preferences.
[See Program](#)

Program Components		
Description of Conceptual or Theoretical Frameworks	Strength-Based Approach, Stress Process Model for Caregivers, and Stress Process Model for persons with dementia	Stress Process Model of Caregiving
One-on-one format	8 in-person sessions for caregivers and persons with dementia	5 in-person sessions for dyad
Session length	1.5 hours	1-1.5 hours
Program length	1.5 months	3 months
Total sessions	8	5
Mode of delivery	In-person	In-person
Program recipient	Caregiver Person with Dementia	Caregiver Family Person with Dementia

Next Steps for Best Practice Caregiving

Seeking 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-US program, programs only for persons with dementia, programs for non-dementia caregivers)

