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Best Practice Caregiving: Guiding Organizations Dementia Programs for Family Caregivers

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Project Team

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The Gerontological Society of America
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Co-Principal Investigator

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

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 |

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


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

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)
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

Methodology for Program Profiling

1. Developer and Distributor Survey
2. Manuals Review
3. Delivery Site Survey
4. Studies Review
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<td>Core of Persons with Dementia in their Environments (CORE)</td>
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<td>Reducing Disability in Alzheimer’s Disease (REDS)</td>
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<td>SCORRE: Together We Can</td>
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<td>UCLA Alzheimer’s and Dementia Care [UCLA ADC]</td>
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### Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS)

Katherine S. Judge, PhD

- **Delivery Person**: Professional or paraprofessional
- **Duration/Format**: In-person sessions for caregivers and persons living with dementia
- **Language**: English
- **Session Length**: 15 hours
- **Program Length**: 13 months

### Active Caregiving: Empowering Skills (ACES)

Sharon Geiger-Thompson, PhD

- **Delivery Person**: Trainer/leads; Professional or paraprofessional
- **Group Format**: In-person or telephone sessions for caregivers
- **Language**: English, Spanish, Vietnamese
- **Session Length**: 2 hours
- **Program Length**: 1 month

### Adult Day Services Plus (ADS Plus)

Laura R. Glidé, PhD

- **Delivery Person**: Professional or paraprofessional
- **Duration/Format**: In-person sessions for caregivers
- **Language**: English
- **Session Length**: Not available
- **Program Length**: 11 months

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### Active Caregiving: Empowering Skills (ACES)

- **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
### Program Overview

**Target Populations**
- **Types of elements:**
  - All types of dementia
  - Other chronic conditions
- **List of other chronic conditions:**
  - Arthritis, Parkinson’s, stroke, cancer, diabetes, dementia, heart disease, high blood pressure, obesity, depression, anxiety

**Program Goals**
- **Cost to Implement:**
  - **Implementation:** $20.00
  - **Annual maintenance:** $50,000
- **Inclusion criteria:**
  - High blood pressure, obesity, diabetes, depression, anxiety
- **Number of deliveries per year:**
  - 1
- **Length of program:**
  - 1 year
- **Annual cost:**
  - $50,000

**Types of assistance programs:**
- **Provided to:**
  - Direct Assistance
  - Information
  - Training
  - Referral

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<thead>
<tr>
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<td>Conducting an Initial Assessment for Dementia-Related Problems or Cognitive Impairment</td>
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<td>Conducting a Reassessment of Dementia-Related Problems</td>
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<td>Coordinating and Monitoring Medical Care</td>
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<td>Coordinating and Monitoring Home and Community Services and Other Community Resources</td>
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<td>Coordinating and Monitoring Assistance from the Network of family and friends</td>
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<td>Relationship of Persons with Dementia and Caregiver</td>
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<td>Transitions in Where Care is Provided</td>
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<td>Understanding or Managing Symptoms of Dementia*</td>
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### Program Characteristics

**Starting**
- Discipline and degree of delivery person:
  - Social Work - Bachelor's
  - Social Work - Master's
  - Nursing - Bachelor's
  - Nursing - Master's
  - Other - Bachelor's
  - Other - Master's
  - Other

**Initial Training**
- Initial training provided: Yes
- Total time: 12 hours
- Number of sessions: 3 sessions
  - Note: Telephone, Satellite or Online
- Procedure for demonstrating mastery
  - Practice sessions on mock cases

**Refresher Training**
- Refresher training provided: No
- Total time: 3 hours
- Number of sessions: 4 sessions per year, 2 sessions for subsequent years. Additional sessions as needed.
  - Note: Telephone, Satellite or Online

**Train-the-Trainer**
- Train-the-Trainer provided: No

**Supervisor Training**
- Supervisor training provided: No

### Survey of Delivery Sites

#### Delivery Site Survey Information
- Number of eligible delivery sites surveyed: 50
- Number of completed delivery site surveys: 30
- Response rate: 60.0%

#### Organization and Program Information
- Delivery history
  - Average number of months site has delivered the program: 16.7
  - Percent of sites that stopped delivering program in the last 12 months: 20%

#### Program User Characteristics
- Number of participants (average in past 12 months):
  - All participants: 1451
  - Persons with dementia diagnosis: 52.7
  - Persons with chronic illness or disabilities, other than dementia or memory problems: 39
  - Family or friend caregiver of persons with dementia diagnosis: 63.7
  - Family or friend caregiver of persons with chronic illness or disabilities, other than dementia or memory problems: 30.5
  - Persons with dementia characteristics (average percent in past 12 months):
    - Under 65 years of age: 4%
    - Living in rural area: 37%
    - Male: 22%
    - Black: 40%
    - Living alone: 4%
    - Experiencing high levels of distress: 27%
    - African American: 39%
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)