Credit Information

- If you are a social worker in a National Association of Social Workers (NASW) state and would like to receive CE credits through NASW for this event, please complete the pre-test posted here: https://www.surveymonkey.com/r/dementiabestpracticespre
  - You will also be required to complete a post-test; a link to this test will appear at the end of the presentation
- For more information about obtaining CE credit for social workers in non-NASW states, psychologists, PAs, nurses (NP, APRN, RN, LPN), pharmacists, marriage and family counselors, etc. or CMEs via the Centers for Medicare & Medicaid Services Learning Management System, please visit: https://resourcesforintegratedcare.com/sites/default/files/GCC_Diagnosing_and_Treating_Dementia_Prewebinar_Continuing_Education_Credit_Guide.pdf

Audio and Platform Information

- The audio portion of the presentation will automatically stream through your computer speakers. If you experience challenges with the audio, please click the phone icon at the bottom of the screen for dial-in information.
- If you are experiencing any technical difficulties with this platform, please use the Q&A feature for assistance or click the help button for additional information.
Diagnosing and Treating Dementia—Current Best Practices
Each session will be interactive (e.g., polls and interactive chat functions), with 60 minutes of presenter-led discussion, followed by 30 minutes of presenter and participant discussions.

Video replay and slide presentation are available after each session at: https://www.resourcesforintegratedcare.com
Accreditation

- Individuals are strongly encouraged to check with their specific regulatory boards or other agencies to confirm that courses taken from these accrediting bodies will be accepted by that entity.

- This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the providership of the Centers for Medicare & Medicaid Services. CMS is accredited by ACCME to provide continuing medical education for physicians.

- The National Association of Social Workers (NASW) is accredited to provide continuing education for social workers.

- CMS is also accredited by the International Association for Continuing Education and Training (IACET). CMS complies with the ANSI/IACET Standard, which is recognized internationally as a standard of excellence in instructional practices. As a result of this accreditation, CMS is authorized to issue the IACET CEU.
Disclosure Statement

As an accredited provider of Continuing Medical Education, the American Geriatrics Society continuously strives to ensure that the education activities planned and conducted by our faculty meet generally accepted ethical standards as codified by the ACCME, the Food and Drug Administration, and the American Medical Association’s Guide for Gifts to Physicians. To this end, we have implemented a process wherein everyone who is in a position to control the content of an education activity has disclosed to us all relevant financial relationships with any commercial interests as related to the content of an education activity has disclosed to us all relevant financial relationships with any commercial interests as related to the content of an education activity has disclosed to us all relevant financial relationships with any commercial interests as related to the content of an education activity has disclosed to us all relevant financial relationships with any commercial interests as related to the content of their presentations and under which we work to resolve any real or apparent conflicts of interest. The existence of commercial or financial interests of speakers related to the subject matter of their presentations should not be construed as implying bias or decreasing the value of their presentations. However, disclosure should help participants form their own judgments. Those speakers who disclosed affiliations or financial interests with commercial interests involved with the products or services to which they may refer are listed below. We have also noted if a speaker has indicated that s/he will be discussing a commercial product or an off-label or investigational use.

The following planners/faculty have returned disclosure forms indicating that they (and/or their spouses/partners) have no affiliation with, or financial interest in, any commercial interest that may have direct interest in the subject matter of their presentation(s):

- **David Reuben, MD**
  No relevant financial interests or affiliations

- **David Bass, PhD**
  No relevant financial interests or affiliations

- **Michelle Panlilio, NP**
  No relevant financial interests or affiliations

- **Ann Cheslaw**
  No relevant financial interests or affiliations
# Continuing Education Information

<table>
<thead>
<tr>
<th>If You Are A:</th>
<th>Credit Options</th>
<th>Requirements</th>
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<td><strong>Option 1: National Association of Social Workers</strong></td>
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<tr>
<td>Social Worker</td>
<td>The National Association of Social Workers designates this webinar for a maximum of 1 Continuing Education (CE) credit hour.</td>
<td>1. Complete the pre-test at the beginning of the webinar 2. Complete the post-test with a score of 80% or higher by midnight <strong>July 31, 2019</strong></td>
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<td><strong>Option 2: Centers for Medicare &amp; Medicaid Services (CMS)</strong></td>
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<td>Physician (MD or DO)</td>
<td>The Centers for Medicare &amp; Medicaid Services (CMS) is evaluating this activity for continuing medical education (CME) credit. The number of credits awarded will be calculated following the activity based on the actual learning time. Final CME information on the amount of credit will be available to participants within the Learning Management System (LMS) after the live activity.</td>
<td>Complete the post-test through CMS’ Learning Management System with a score of 80% or higher by midnight <strong>August 19, 2019</strong></td>
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<tr>
<td>Other</td>
<td>The Centers for Medicare &amp; Medicaid Services (CMS) is evaluating this activity for continuing education (CE) credit. The number of credits awarded will be calculated following the activity based on the actual learning time. Final CE information on the amount of credit will be available to participants within the Learning Management System (LMS) after the live activity.</td>
<td>Complete the post-test through CMS’ Learning Management System with a score of 80% or higher by midnight <strong>August 19, 2019</strong></td>
</tr>
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</table>
Support Statement

- This webinar is supported through the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) to help beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated, coordinated care to dually eligible beneficiaries, MMCO is developing technical assistance and actionable tools based on successful innovations and care models, such as this webinar.

- To learn more about current efforts and resources, visit Resources for Integrated Care at: https://www.resourcesforintegratedcare.com
Introductions

- **David Reuben, MD**
  Chief, Division of Geriatrics at the David Geffen School of Medicine at UCLA; Director, UCLA Alzheimer’s and Dementia Care Program

- **David Bass, PhD**
  Senior Vice President and Director of the Center for Research and Education, Benjamin Rose Institute on Aging

- **Michelle Panlilio, MSN, NP**
  Dementia Care Specialist and Nurse Practitioner, UCLA Alzheimer's and Dementia Care Program

- **Ann Cheslaw**
  Family Caregiver
Learning Objectives

1. Identify best practices and guidelines for screening, diagnosis, and assessment of dementia in older adults, including those who are dually eligible

2. Identify current evidence-based pharmacologic and non-pharmacologic treatment options that mitigate symptoms of dementia in older adults, including those who are dually eligible

3. Recognize the important roles of caregivers in managing dementia and interventions for supporting caregivers of older adults with dementia, including those who are dually eligible

4. Recognize roles and strategies for community-based organizations and health systems in supporting older adults with dementia and their caregivers, including those who are dually eligible
Webinar Outline/Agenda

- Polls
- Overview of diagnosis, treatment, and management of dementia in older adults
- Community-based programs for older adults with dementia and their caregivers
- Health system-based programs for older adults with dementia and their caregivers
- A family caregiver’s story
- Q&A
- Evaluation
Overview of Diagnosis, Treatment, and Management

David Reuben, MD
Chief, Division of Geriatrics at the David Geffen School of Medicine at UCLA
Director, UCLA Alzheimer’s and Dementia Care Program

UCLA Health System
Geriatric Medicine
What Did These People Have In Common?

Glen Campbell, Singer
Rita Hayworth, Actress
Gene Wilder, Actor
President Ronald Reagan
Charlton Heston, Actor
What is Dementia?

- 2011 National Institute on Aging (NIA) definition of dementia:\(^1\)
  - A chronic acquired decline not explained by delirium or psychiatric disorder in a minimum of two of the following domains:
    - **Impaired ability to acquire and remember information** – (e.g., repetitive questions, misplacing belongings, forgetting events)
    - **Impaired reasoning and handling of complex tasks** – (e.g., poor understanding of safety risks, inability to manage finances)
    - **Impaired visuospatial abilities** – (e.g., inability to recognize faces or common objects or find objects)
    - **Impaired language functions** – (e.g., difficulty thinking of common words when speaking; speech, spelling, and writing errors)
    - **Changes in personality, behavior, or comportment** – (e.g., uncharacteristic mood fluctuations)
  - Sufficient to affect daily life

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The Gray Plague

- **Prevalence of dementia**

<table>
<thead>
<tr>
<th>Age Range</th>
<th>% Affected</th>
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<tbody>
<tr>
<td>65-74 years</td>
<td>3-5%</td>
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<tr>
<td>75-84 years</td>
<td>15-25%</td>
</tr>
<tr>
<td>85 years and older</td>
<td>32-50%</td>
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</tbody>
</table>

- **Causes of dementia**

<table>
<thead>
<tr>
<th>Cause</th>
<th>% Affected</th>
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</thead>
<tbody>
<tr>
<td>Alzheimer’s disease</td>
<td>60-80%</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>10-20%</td>
</tr>
<tr>
<td>Dementia with Lewy bodies</td>
<td>15%</td>
</tr>
<tr>
<td>Frontotemporal dementia</td>
<td>5%</td>
</tr>
<tr>
<td>Toxic-metabolic disorders</td>
<td>4%</td>
</tr>
<tr>
<td>Other movement disorders</td>
<td>6%</td>
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</tbody>
</table>

5.8 million Americans have Alzheimer’s disease, the most common type of dementia, including an estimated 5.6 million people ages 65 and older. By 2050, the number of Americans living with Alzheimer’s disease will triple as the population ages.

27% of people with dementia who are receiving Medicare benefits are dually eligible for Medicaid.

In 2019, Medicare and Medicaid will spend an estimated $195 billion caring for those with Alzheimer’s and other dementias—67% of total costs for both programs.

An estimated $146 billion dollars will be spent under Medicare and $49 billion under Medicaid.

Unpaid caregivers provide 83% of total care to persons with dementia.

In 2018, 18.5 billion hours of care, valued at $234 billion, were provided by family, friends, and other unpaid caregivers.


Alzheimer’s Disease: A Two-Phase Strategy

Now

Have Dementia

5.8 million

Phase 1

Detection
Treatment
Support

Health Care System

Community

Phase 2

Risk Factor Identification
Monitoring
Prevention
Detection
Treatment
Support

Health Care System

Community

2030

Will Develop Dementia

7.7 million
Detection

- Screening is often the first step of detection
  - 3 item recall
  - Mini-Cog (3 item recall plus clock drawing)
  - Mini-Mental State Examination (MMSE), Montreal Cognitive Assessment (MoCA), and others

- Screening tests identify more than 90% of individuals with dementia (missing around 10%) but do not establish a diagnosis\(^7\)

- A 2014 US Preventive Services Task Force (USPSTF) evidence review found insufficient evidence to assess the balance of benefits and harms of systematic screening\(^8\)


Diagnosis

- Clinician’s examination
  - Onset and descriptions of symptoms (e.g., had trouble paying bills, forgot appointments, repeated questions for the last year)
  - Behavioral problems (e.g., agitation, wandering)
  - Functional status (e.g., inability to cook, bathe, dress)
- Neurologic exam
  - Motor (e.g., signs of previous stroke)
  - Gait (e.g., asymmetry, instability)
  - Parkinson’s symptoms (e.g., tremor, rigidity)
Diagnosis (Continued)

- Clinician’s examination - Mental Status Exam
  - Useful in establishing the diagnosis
    - Memory - word list recall and retention; and remote memory (things and events from years earlier)
    - Language-Semantic Fluency (e.g., animal naming)
    - Problem solving
    - Clock drawing
  - Useful in identifying complications
    - Neuropsychiatric Inventory (NPI)
    - Cornell Scale for Depression in Dementia
Neuropsychological testing (extensive battery of tests done by a psychologist) is primarily used when the diagnosis is unclear.

Lab tests used to exclude medical conditions (e.g., hypothyroidism, chronic kidney disease) that might be contributing:

- Complete blood count (CBC), comprehensive metabolic panel (CMP), thyroid-stimulating hormone (TSH), B12
- Syphilis and HIV only if specific risk factors
Neuroimaging and cerebrospinal fluid (CSF) testing may add diagnostic accuracy to clinical evaluation

- CSF testing generally based on evaluation by a neurologist

Neuroimaging is most useful if:

- Age of onset <60 years
- Focal neuro deficits (e.g., unilateral weakness, sensory deficits)
- Abrupt onset or rapid decline
- Predisposing conditions (e.g., cancer, blood thinners)

CT or MRI (more sensitive): recommended by American Academy of Neurology (AAN)

Positron emission tomography (PET): approved to distinguish Alzheimer’s disease from frontotemporal dementia (FTD)

Amyloid PET: for research purposes only
Principles of Managing Dementia

- Work with the person and their caregiver
  - This is a lifelong disease – acknowledge this fact in your conversations with the person and their supports
- Use person-centered care
  - Include individuals directly in ongoing discussion about their care
  - As the disease progresses, rely more on family and caregivers
- Aim for the highest level of independence and self-determination for the diagnosed individual that works for everyone involved
Work with the Individual

- Manage common challenging issues (e.g., driving, living alone)
- Manage symptoms (e.g., agitation, wandering, aggression)
  - Drug management of complications
  - Behavioral therapies
- Advanced care planning
- Care management and coordination
- Manage co-morbidities
- Caregiver support
Managing Dementia: Medications

- Cholinesterase Inhibitors (all have generics) are prescribed to treat the cognitive symptoms of dementia
  - Common medications: Donepezi, Galantamine, Rivastigmine (oral or transdermal, fewer GI effects)
- Benefit of these medications is small (~10% improve, ~20% less decline) but may be use useful for these types of dementia:
  - Alzheimer’s disease
  - Dementia with Lewy Bodies
  - Vascular (if AD also present)
  - Parkinson’s disease dementia
- Cholinesterase inhibitors are not effective for:
  - Treatment of frontotemporal degeneration
  - Preventing the progression of mild cognitive impairment (MCI) to dementia
Memantine (generic)

- FDA approved for moderate-severe Alzheimer’s disease
- Effects are less evident in mild-moderate disease
- Overall, evidence suggests that memantine leads to inconsistent effects on cognition, no difference in function, and small improvements in clinical impression of change
- In moderate to severe dementia, when added to a cholinesterase inhibitor, memantine has:
  - Inconsistent effects on cognition
  - No effect on function
  - Small benefit on clinician impression of change plus caregiver input
- Combination tablet is much more expensive
Managing Dementia: Medications (Continued)

- Treatments that do not improve symptoms of dementia:
  - Vitamin B6, B12, or folate (unless deficient)
  - Gingko biloba
  - Hormones (testosterone, estrogen)
  - Statins
  - Aspirin or other NSAIDs
  - Anti-amyloid treatment
  - Exercise (in persons with mild to moderate dementia)
Managing Behavioral and Psychological Complications

- Good evidence for formal caregiver training
- Music therapy may improve symptoms of depression and overall behavioral issues but additional research is needed\(^9\)
- Others (e.g., cognitive stimulation, reminiscence, validation, exercise, animal-assisted therapy) have limited evidence

Managing Behavioral and Psychological Complications (Continued)

- Potential medication options for behavioral and psychological complications:
  - Antidepressants
    - SSRIs – evidence of improvements in agitation but may hasten cognitive decline
  - Atypical antipsychotics
    - Not very effective but some persons with dementia benefit
    - Have potential for side effects
    - Small increase in mortality rates due to cardiovascular issues or infection
  - Dextromethorphan-Quinidine
    - Modest improvement in 1 randomized control trial
  - Mood stabilizing medications (little evidence for use)
    - Valproate
    - Carbamazepine
    - Lithium
Support for Unpaid Caregivers

- Unpaid caregivers are the most important resource for an individual who has dementia
  - Over 50% of caregivers develop depression
  - The more knowledgeable and empowered the caregiver is, the better the care they can provide

- Examples of unpaid caregiver training/support programs
  - Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) – 12 individual and 5 telephone support groups over 6 months
  - New York University Caregiver Intervention (NYUCI) – 2 individual counseling sessions, 4 family counseling sessions, weekly support groups, ad-hoc counseling
  - Alzheimer’s Association and other community resources
  - Area Agency on Aging – https://eldercare.acl.gov/Public/Index.aspx

New Models of Comprehensive Care for Dementia

- Focus on client and caregiver
- Community-based examples
  - Benjamin Rose Institute (BRI) Care Consultation\(^{13}\)
  - Maximizing Independence at Home (MIND at Home)\(^{14}\)
- Health System-based examples
  - Indiana University Healthy Aging Brain Center (HABC)\(^{15}\)
  - The UCLA Alzheimer’s and Dementia Care Program (UCLA ADC)\(^{16}\)

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Non-pharmacological Programs for Caregivers of Persons Living with Dementia

David Bass, PhD
Senior Vice President
Benjamin Rose Institute on Aging
Benjamin Rose Institute on Aging: Highlighting Two Key Resources

- Benjamin Rose Institute on Aging
  - Cleveland nonprofit that provides services and conducts research to advance support for older adults and family/friend caregivers

- Highlighted Resources
  - *Best Practice Caregiving* – Online compilation of dementia caregiving programs
  - BRI Care Consultation Program – Care-coaching program helping professionals support people with dementia and their unpaid caregivers
Best Practice Caregiving

- Easy-to-use online compilation for healthcare and social service organizations, policy makers, and funders of services to get comprehensive descriptions and compare 45 evidence-based dementia caregiving programs
  - Comprehensive program profiles
  - Detailed information about program implementation features
  - Experiences of non-research delivery sites
  - Key features and findings from evidence-based research
  - Complete program bibliographies
  - Contact information for program developers or distributors

Goal – Increase program replications and the availability of proven program to families

Status: Beta testing in progress, planned public launch in Fall 2019
Best Practice Caregiving: Collaborators

- A collaboration between Benjamin Rose Institute on Aging and Family Caregiver Alliance:
  - Family Caregiver Alliance is a San Francisco nonprofit dedicated to promoting health and well-being of unpaid family/friend caregivers through information, education, support, and research

- Funders:
  - The John A. Hartford Foundation
  - Archstone Foundation
  - The Retirement Research Foundation
Why Create Best Practice Caregiving?

Prior to the tool, there was no comprehensive updated source of detailed information on evidence-based programs for caregivers and persons living with dementia\textsuperscript{17}

- Limited information in published articles - particularly about implementation experiences and delivery tools
- Lack of easy-to-find, detailed program descriptions makes it difficult to know which programs are:
  - Best match for a particular organization or community
  - Ready for non-research community implementation
  - Being delivered and working well in other communities

Why Create *Best Practice* Caregiving?

- Many non-pharmacological programs have proven benefits for unpaid family/friend caregivers
  - Some of these programs *also* have proven benefits for persons living with dementia
- Despite proven benefits, the use of programs aimed at unpaid caregivers is still limited:\[^18]\n  - Most health and social organizations do not offer any of these programs
  - Most programs are not accessible to unpaid caregivers

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Eligibility Criteria for Inclusion in Best Practice Caregiving

1. At least 1 completed US-based study that was a randomized controlled trial, non-randomized controlled trial, or pre-post-test without control group.
   - At least 50% of sampled caregivers assisting a person living with dementia in the community
   - At least one statistically significant, published, beneficial caregiver outcome

2. At least 1 other implementation, where the program was delivered by a health or social service organization as a regular service.
   - Serve at least some caregivers of person living with dementia living in the community

3. Permission and/or license to deliver the program is available, along with delivery tools such as manuals, training for delivery staff, and marketing tools.
# Programs Featured in Best Practice Caregiving (Phase I)

<table>
<thead>
<tr>
<th>Programs</th>
<th>ACCESS</th>
<th>EPIC</th>
<th>REACH VA</th>
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<td>ACCESS</td>
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<td>REACH VA</td>
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<td>Savvy Caregiver</td>
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<td>Inner Resources for Stress</td>
<td>Scott &amp; White Family Caregiver Program</td>
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<td>Memory Club</td>
<td>SHARE</td>
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<td>ANSWERS</td>
<td>Mindfulness-Based Alzheimer’s</td>
<td>Skills2Care</td>
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<td>At the Crossroads</td>
<td>Caregiving Program</td>
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<td>Mindfulness-Based Stress</td>
<td>Stress-Busting Program</td>
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<td>Behavioral Treatment of Insomnia for Caregivers</td>
<td>Reduction for Caregivers of Frail Elderly</td>
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<tr>
<td>BRI Care Consultation</td>
<td>Mindfulness-Based Stress</td>
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<td>Reduction for Dementia Caregivers</td>
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<td>Building Better Caregivers</td>
<td>Minds in Motion</td>
<td>Tailored Activities Program (TAP)</td>
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<td>CALMA: Reach to Caregivers</td>
<td>Mindfulness Training for Patients with Progressive Cognitive Decline and their Caregivers program</td>
<td>TCARE®</td>
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<td>New York University Caregiver</td>
<td>Telenovela Mirela</td>
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<td>Central Texas Community Living Program</td>
<td>Intervention (NYUCI)</td>
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<td>Collaborative Care</td>
<td>RCI REACH</td>
<td>Together We Can! Facing Memory Loss as a Family</td>
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<td>COPE</td>
<td>Reducing Disability in Alzheimer’s Disease (RDAD)</td>
<td>UCLA Alzheimer’s and Dementia Care</td>
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<tr>
<td>Dealing with Dementia</td>
<td>REACH Community</td>
<td>Yogic Meditation</td>
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Best Practice Caregiving
Program Topic Examples

- Managing/Understanding Symptoms
- Health and Wellness
- Coping with Illness/Caregiving
- Relationship of Caregiving Dyad
- Planning for Care
- Involving Family/Friends
- Effective Communication between Caregiver and Person
- Daily Tasks
- Diagnosis or Prognosis of Dementia
- Medical Care
- Assessing Symptoms and Care
- Transitions in Care
- Financial Issues Related to Care
- End-of-Life Care
- Coordination and/or Monitoring Care and Services
Best Practice Caregiving Program
Formats and Characteristics

Formats
- Group, Individual, or Dyad
- Time Limited with 2-12 Sessions or Ongoing

How Assistance is Provided
- Direct help, Counseling, or Coaching
- Training for Caregivers to Enhance Skills
- Education or Information about Illness, Symptoms, Care, or Services
- Linking and/or Coordinating Care and/or Services

Modes of Delivery
- In-person
- Telephone
- Online, Email, Webinars
- Combinations
Timeline for Launch of Best Practice Caregiving

- **2018**
  - Program Profiling

- **2018**
  - Initial Website Design

- **July-Sept. 2019**
  - Beta Testing

- **Fall 2019**
  - Public Launch and Evaluation

Marketing and Updating
BRI Care Consultation: One of the Programs Included in *Best Practice Caregiving*

- An evidence-based care-coaching program that helps professionals deliver cost-effective assistance and support to individuals with chronic conditions and caregivers by telephone and email.
- Proven efficacy, effectiveness, and feasibility in 10 completed research studies; 3 additional research studies underway.
- Licenses marketed to healthcare and social service organizations by Benjamin Rose Institute on Aging.
  - Over 40 currently licensed delivery sites.
  - Most licensed sites are Area Agencies on Aging, Health Systems, Alzheimer’s Chapters, and other Alzheimer’s Organizations.
Why Create the BRI Care Consultation?

- Caregiver challenges
  - Wanting help but not knowing where to begin
  - Lack of coordination among family and friend caregivers

- Service system and/or provider challenges
  - Fragmentation and lack of coordination among services
  - Lack of attention by some service providers to planning, prevention, and caregiver needs
  - Tendency for too much assessment by service providers but too few solutions
  - Services not adjusting to changes in health condition and caregiver capacity
BRI Care Consultation as a Solution

- Consumer-driven approach that supports the person with chronic condition and family preferences
- Cost-effective delivery by telephone, email, and regular mail
- Serves person with chronic condition and/or their family/friend caregiver
- Provides personalized coaching focused on simple and practical solutions
- Maintains a longer-term relationship with clients
- Responds to changing needs
- Aims to prevent crises and plan for the future
- Follows a standardized protocol with personalized content
Assistance Provided by BRI Care Consultation

- Links to and coordinates use of health and community services
- Helps resolve barriers to service use
- Promotes greater involvement of family and friends in care
- Offers coaching and emotional support
- Provides consumer-ready informational and educational materials
Key Components of the BRI Care Consultation

- **Assessment**: To help families identify problems
- **Action Plan**: To move toward solutions
- **Ongoing Support**: As care situation changes
BRI Care Consultation: Assessment

- Identify and address holistic range of possible medical and non-medical concerns of the individual and the caregiver
- Complete by having discussions (rather than a battery of clinical testing)
- Care Consultants check-in by asking about any concerns or needed assistance with 24 domains the individual and 11 domains for the caregiver
- Complete initial assessment over the first four months
- Reassess (i.e., discuss) each medical and non-medical domain twice annually
- Flexible program assists persons without caregivers, caregivers can not or does not want to participate, and caregiving dyads
BRI Care Consultation: Action Plan – Key to Program Success

- Begin forming the Action Plan during the first phone contact (do not wait for initial assessment)
- Address concerns that are the priorities of the individual and caregiver
- Care Consultants, in partnership with individual and caregiver, create the plan that includes an evolving set of simple, personalized and achievable “Action Steps” (periodically send a copy to clients)

Action Steps are:
- Assigned to a specific person to complete
- Have expected completion dates and scheduled follow-ups
- New Action Steps prompted by barriers to completion of prior Action Step
- Most common Action Steps relate to: contacting services, reading consumer-ready information, and asking/getting other family and friends to help
<table>
<thead>
<tr>
<th>Action Step</th>
<th>Who will do?</th>
<th>By When?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Provide list of &quot;dementia-friendly&quot; community settings, including businesses where Tom and Joan will be more comfortable frequenting, especially due to Tom’s anxiety when outside the home.</td>
<td>Jackie Mathers</td>
<td>8/2/2019</td>
</tr>
<tr>
<td>2. Contact Sunshine Senior Companion Program at 555-555-5555 and inquire about Tom enrolling in the Program and receiving Senior Companion visits.</td>
<td>Joan Cooper</td>
<td>8/16/2019</td>
</tr>
<tr>
<td>3. Attend exercise class 3-5 times a week at Community Recreation Center (yoga class meets at 10am and light aerobics meets at 4pm Monday through Friday) while Tom participates in walking group.</td>
<td>Joan Cooper</td>
<td>8/30/2019</td>
</tr>
<tr>
<td>4. Discuss Tom’s sleeping difficulties and wandering concerns at night with Dr. Rogers, Tom’s primary care physician during next appointment.</td>
<td>Joan Cooper</td>
<td>8/31/2019</td>
</tr>
<tr>
<td>5. Install nightlights throughout the home, install door alarm monitor for front and rear door, and secure rugs to the floor to prevent Tom from falling when he wakes up at night.</td>
<td>Joseph Cooper</td>
<td>9/6/2019</td>
</tr>
<tr>
<td>6. Visit father two days per week and engage him in his favorite activities (i.e., discussing current events, chess, and walking).</td>
<td>Joseph Cooper</td>
<td>9/30/2019</td>
</tr>
<tr>
<td>7. Attend Early Stage Support Group at the Alzheimer’s Association, 959 Main Street, AnyCity, OH on the third Thursday of each month at 2pm.</td>
<td>Joan Cooper</td>
<td>11/30/2019</td>
</tr>
<tr>
<td>8. Drive and attend church services with Thomas twice a month.</td>
<td>Rhonda Davidson</td>
<td>11/30/2019</td>
</tr>
<tr>
<td>9. Drive Thomas to Sunshine Adult Day Program on Monday, Wednesday, and Friday mornings at 9am on her way to work.</td>
<td>Linda Wilson</td>
<td>12/31/2019</td>
</tr>
<tr>
<td>10. Attend Sunshine Adult Day Program three times/week – Mondays, Wednesdays, and Fridays from 9am-2pm.</td>
<td>Tom Cooper</td>
<td>12/31/2019</td>
</tr>
</tbody>
</table>
BRI Care Consultation: Ongoing Support

- Schedule ongoing follow-up contacts at enrollment to maintain connection and facilitate monitoring
  - More frequent contacts can be initiated by clients or Care Consultants
- Conduct additional follow-up calls to check progress on Action-Step completion
- Offer program for at least 6 months – can be used longer depending on delivery organization’s and client’s preferences
BRI Care Consultation: Care Consultant Role

• Care consultants have:
  • At least a Bachelor’s degree in SW, RN, or other helping profession
  • Program training and support provided by Benjamin Rose Institute on Aging
• One full-time Care Consultant maintains a caseload of 75-125 families
• Care consultants are able to coach families in a consumer directed program
Web-Based Care Consultation Information System

- Platform for delivery that mirrors the scientifically-proven program
- Drives/reinforces the programs’ main components
- Promotes standardized, quality delivery
- Includes reports for monitoring quality, program fidelity, and staff performance
- Library of 700+ vetted consumer-ready informational/educational resources
Demonstrated BRI Care Consultation Outcomes after 6 or 12 Months

<table>
<thead>
<tr>
<th>FAMILY/FRIEND CAREGIVER Psychosocial Outcomes (self-report)</th>
<th>PERSON WITH CHRONIC CONDITION Psychosocial Outcomes (self-report)</th>
<th>Service Use Outcomes (records-based)</th>
</tr>
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<tbody>
<tr>
<td>18% Fewer unmet needs</td>
<td>36% Fewer unmet needs</td>
<td></td>
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<tr>
<td>21% Fewer symptoms of depression</td>
<td>80% Fewer symptoms of depression</td>
<td></td>
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<tr>
<td>22% Less health strain</td>
<td>55% Less relationship strain with caregiver</td>
<td></td>
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<tr>
<td>20% Less feeling of being trapped in caregiving</td>
<td>20-50% Fewer emergency department visits</td>
<td></td>
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<tr>
<td></td>
<td>1 less hospital readmission</td>
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</tbody>
</table>
UCLA Alzheimer’s and Dementia Care Program

Michelle Panlilio,
MSN, NP
Dementia Care Specialist and Nurse Practitioner, UCLA Alzheimer's and Dementia Care Program
Health-System Based Care Programs for Alzheimer’s and Dementia

- Care programs for Alzheimer’s and Dementia care that are implemented in health systems typically include the following:
  - Leadership by a nurse practitioner or physician
  - Face-to-face annual visits
  - Coordination within health system and the electronic health record system
  - Order writing (medications, equipment, referrals to other services)
  - Home visits (in some programs)

- Program goals include:
  - Better quality of care
  - Reduced caregiver burden/strain/depression
  - Reduced nursing facility placement
  - Lower health care costs

- Examples:
  - Indiana University Healthy Aging Brain Center (HABC)
  - The UCLA Alzheimer’s and Dementia Care Program (UCLA ADC)
UCLA Alzheimer’s and Dementia Care (ADC) Program

- Goals of the ADC program:
  - Maximize patient function, independence, and dignity
  - Minimize caregiver strain
  - Reduce unnecessary costs

- History
  - Began in 2011 with philanthropic funds - originally planned to enroll 250 individuals
  - Round 1 CMMI Award July 2012—Dec 2015 - expanded the program to 1,000 individuals
  - Now, over 2,600 individuals are enrolled; ~700 active
Patient Eligibility and Philosophy

- **Patient Eligibility**
  - Must have diagnosis of dementia
  - Must live outside of a nursing facility
  - Must have a referring/partnering UCLA physician
  - Must have a family member/caregiver willing to participate in care

- **Philosophy**
  - Approaches the patient and caregiver as a dyad; both need support
  - Recognizes that care for Alzheimer’s and dementia is a long journey
  - Provides comprehensive care based in the health system that reaches into the community
Staffing: Role of Dementia Care Specialists

- Co-management model with Nurse Practitioner Dementia Care Specialist (DCS)
- DCS staff do not assume primary care of the patient; they work with physicians to provide dementia care for patients by:
  - Conducting in-person needs assessments
  - Developing and implementing individualized dementia care plans
  - Monitoring response to the care plan and revising as needed by phone, office visits, and emails
  - Providing access 24 hours/day, 365 days a year
Initial Assessment

- Meet with patient and caregiver (90 minutes)
  - Review dementia history
  - Complete focused physical and mental status exam
  - Discuss current concerns (e.g., meds, behaviors, safety)
  - Assess resources
  - Discuss advance care planning
  - Determine any needed education or support
  - Establish co-management w/ referring MD
Patient Acuity

- **Red**
  - 2 or more ER visits in past 6 months
  - Uncontrolled or problematic behavioral issues (likely inpatient psychiatric hospital admission)
  - Follow-ups: at least monthly

- **Yellow**
  - 1 ER visit past 6 months
  - New or worsening behavioral issues
  - Follow-ups: at least every two months

- **Green**
  - 0 ER visits past 6 months
  - No behavioral issues
  - Follow-ups: at least every three months
Ongoing Care

- Follow up phone calls to touch base, frequency determined by patient acuity
  - Additional phone calls as needed
- Follow up in-person visits if needed or desired
- Phone call after ED visits and hospitalizations
- Annual in-person visit with patient and caregiver
Establishing Relationships with Community-Based Organizations (CBOs)

- Assess CBOs as potential partners by considering:
  - Location, parking, nearby traffic congestion
  - Safety of the area where CBO is located
  - Cost of services
- Identify key personnel within each organization and make formal introductions to key ADC staff
- Obtain a list of services provided by each CBO
- Perform site visits to determine suitability of services and programs for ADC patients and families
- Consider vouchers for services to standardize the process of referrals and payments
  - Helpful for patients and families with limited financial means
  - Issued as a gift certificate that patient/caregiver can redeem for services
Services Provided by Partner CBOs

- **Services for patients:**
  - Adult day services
  - Programs for enhancing brain health (for early stage memory loss)

- **Services for families/caregivers:**
  - Education (workshops, classes, informational sessions, handouts)
  - Counseling and peer-to-peer support
  - Case management
  - Legal and financial counseling
  - Support groups
Subset of Partners with whom ADC Partners

- Alzheimer’s Association (CA Central and Greater LA)
- OPICA
  - Adult day services
  - Support groups for caregivers
  - Case management
- Jewish Family Services
- Leeza’s Care Connection
- ONEgeneration
- Senior Concerns
- Coast Caregiver Resource Center
Common Barriers for Patients and Caregivers When Working with CBOs

- No specific contact person or number provided for the CBO
  - Once your program has established a working relationship with the CBO, request for them to provide the name and contact information of their responsible personnel for specific services (warm handoff)
  - Follow up with the patient/caregiver regarding whether they were able to establish care

- Caregiver/family is not knowledgeable about services provided
  - Recommend specific services (not generalized) that are appropriate for the patient and family
Common Barriers for Patients and Caregivers When Working with CBOs (Continued)

- Caregivers may be experiencing burnout or ambivalence toward engaging services
  - Discuss importance of self-care
  - Explain potential benefits for both the patient and the caregiver

- Financial limitations
  - Determine if the patient/family is able to afford the service
  - If finances are limited, assist the family in applying for government aid such as Medicaid or Veteran’s Benefits
  - Consult CBO if they have any scholarship/grant programs for their services
Role of the ADC Steering Committee

- The ADC Steering Committee is a vital method for establishing strong relationships with CBOs
  - Consists of key personnel in the ADC Program, representatives from CBOs, as well as caregivers actively participating in ADC
  - Holds bi-annual meetings
- Agendas include
  - ADC program updates
  - ADC awards and achievements
  - Planning for ADC future goals
  - Introduction of new staff in program
Patients in the ADC Program

- Diagnosis
  - Alzheimer’s disease: 35%
  - Lewy-Body dementia: 4%
  - Vascular dementia: 4%
  - Other, mixed or unknown: 53%

- Mini-Mental State Examination score: 17.4 (mean)
- Caregiver: 41% spouse, 59% child
- Gender: 67% female
- Insurance status: 11% dually eligible
1-Year Outcomes: Patients

- After 1 year in the program, patient:
  - Overall cognition and functional status declined
  - Behavioral symptoms of depression improved
Assessment of Unpaid Caregivers at Entry to ADC Program

- Experiencing moderate to severe depressive symptoms: 14%
- Reporting high stress levels: 36%
- Experiencing low self-efficacy
  - Knowledge of how to access needed services: 21%
  - Feeling confident in handling patient’s dementia diagnosis: 36%
- Feeling “alone”
  - Reporting that the patient's doctor understands how memory or behavior problems complicate other health conditions: 80%
  - Reporting that they have access to a healthcare professional who helps work through dementia-related issues: 26%
Caregiver Satisfaction with the ADC Program

- Caregivers who reported that the intake visit was time well spent: 90%
- Caregivers who reported that they felt their concerns were listened to and addressed: 91%
- Caregivers who reported that they would recommend the program to others: 92%
1-Year Outcomes: Caregivers

- After 1 year in the program, caregiver:
  - Distress from patient behavioral symptoms was reduced
  - Overall strain was less
  - Depressive symptoms were reduced
1-Year Changes in Caregiver Experience and Self-Efficacy

- 60% of caregivers indicated they were better able to find community-based services
  - 20% before the ADC program
- 62% of caregivers were confident they could handle dementia-related issues (e.g., medications, finances, behaviors, advanced care planning)
  - 32% before ADC program
- 78% of caregivers reported knowing where to turn to get answers
  - 35% before ADC program
- 76% of caregivers reported having access to a healthcare professional who helps
  - 25% before the ADC program
UCLA ADC: The Triple Aim

- Patient Experience (Better Care)
- Health of Populations (Better Health)
- Reducing per capita cost (Better Value)
The UCLA ADC Program Results

- **Better Care:**
  - Met at least 90% of ACOVE and PCPI dementia quality indicators\(^\text{19}\)
  - Satisfies all 5 dementia MIPS measures (Cognitive assessment, Functional Status assessment, Neuropsychiatric Symptom assessment, Counseling regarding safety concerns, Caregiver Education and support)
  - Physicians report that it saves them time and DCSs make valuable social and medical recommendations
  - High caregiver satisfaction
  - High physician satisfaction

- **Better Health:**
  - Improved confidence and self-efficacy
  - Improved patient behavioral and depressive symptoms
  - Improved caregiver strain, depressive symptoms, and distress

1-year Physician Satisfaction with the ADC Program

- Of the 279 referring physicians who reported on satisfaction,
  - 61% said the program made valuable medical recommendations
  - 85% said the program made valuable behavioral recommendations
  - 68% reported an enhanced relationship with patients
  - 56% reported that the program saved them time
  - 90% would recommend for other patients
2-Year Impact to Utilization and Costs

- ED visits: 20% reduction*
- ICU stays: 21% reduction
- Hospital days: 26% reduction*
- Hospice in last 6 months: 60% increase*
- Total Medicare costs of care: $2404/year*
- Nursing facility placement: 40% reduction*

* p<.05

Based on NORC external evaluation of CMMI Award using fee-for-service claims data and UCLA ACO data September 2015-September 2017
Diagnosing and Treating Dementia – Current Best Practices

A Family Caregiver’s Perspective

Ann Cheslaw
Family Caregiver
Tips from a Caregiver

1. Encourage families – especially those with a genetic disposition to Alzheimer’s – to work with a geriatrician sooner rather than later. Help them select a practitioner who is a teacher and one who values a patient’s individual life’s narrative as part of his/her wellness.

2. Understand that caregivers don’t have time to seek out community resources and educational tools to help them learn. Direct them to these. Online videos (e.g. UCLA’s - https://www.uclahealth.org/dementia/caregiver-education-videos) and podcasts, rather than reading materials, are ideal. There need to be more!
Tips from a Caregiver

3. Remind families that this disease is not linear; there will be good and bad days. Let families know that their frequency in showing up at living facilities, nursing homes, and in hospitals often correlates with the improvement in personalized care their special person gets.

4. Assure family members that self-care is critical as they cope with their own predictable senses of isolation, inadequacy, fear, and anxiety about the future.

And finally…
5. Urge caregivers to remember to sing...regardless of how off key they may be!
Conclusions

- The number of persons with Alzheimer’s disease and related dementias is rising rapidly as the baby boomers age.
- In the future, there may be better methods to identify and modify risk, prevent the development of dementia, and treat dementia.
- Currently, the care of dementia relies on detection, medications with modest effectiveness, and support, including caregiver training and support, case management, and care coordination.
- Effective models are available but have not been adopted widely.
- Every dementia story is unique and has multiple victims, the person with disease and the caregivers.
Questions
Additional Resources

Tools available for download at: www.AlzheimersLA.org/professionals

- Sample HRA Questions
- Training Curricula for Care Managers
- Direct Referral Form (for adaptation)
- Dementia Care Management Toolkit
- Dementia Screening Tools
- Caregiver Identification Tool
- Caregiver Assessment Scales
- Care Needs Assessment Tool
- IDEA! Strategy for Managing Challenging Behaviors
- Best Practice Care Plans
- Plain Language Caregiver Tip Sheets
- Advocacy materials

Additional caregiver education videos: http://dementia.uclahealth.org/caregiver-education-videos

Resources from the National Alzheimer's Project Act (NAPA): https://aspe.hhs.gov/national-alzheimers-project-act
These tip sheets summarize information from previous webinars for the use and reference of care coordinators, case managers and other non-clinical people who support people with dementia:

- Applying Promising Practices To Advance Care For Individuals Dually Eligible For Medicare And Medicaid With Dementia
- Beyond Alzheimer’s Disease – Other Causes Of Progressive Dementia In The Older Adult

Visit the Alzheimer’s Disease And Other Related Dementias (ADRD) page for additional resources

Visit https://resourcesforintegratedcare.com/ to view previous webinars and obtain continuing education credit
Thank You for Attending!

- The video replay, slide presentation, and a summary of the Q&A will be available at: https://www.resourcesforintegratedcare.com/GeriatricCompetentCare/2019_GCC_Webinar/Diagnosing_and_Treating_Dementia

- If you are applying for NASW CE, you must complete the post-test in order to receive credit: https://www.surveymonkey.com/r/dementiabestpracticespost

- For more information about obtaining CMEs or CEUs via CMS’ Learning Management System, please visit: https://resourcesforintegratedcare.com/sites/default/files/GCC_Diagnosing_and_Treating_Dementia_Prewebinar_Continuing_Education_Credit_Guide.pdf

- Questions? Please email RIC@lewin.com

- Follow us on Twitter at @Integrate_Care to learn about upcoming webinars and new products!
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We would also like to invite you to provide feedback on other RIC products as well as suggestions to inform the development of potential new resources: https://www.research.net/r/MVGNWVJ


Sources and Citations


