National Coalition on Mental Health and Aging
and
National Council on Aging
PRESENT
The Invisible Health Care Provider: Family Caregivers of Individuals with Dementia
2019-2020
November 13, 2019
Mission:
To provide opportunities for professional, consumer and government organizations to work together towards improving the availability and quality of mental health preventive and treatment strategies to older Americans and their families through education, research and increased public awareness.

Visit: www.ncmha.org
History, Membership and Activities:

• Formed in 1991 by a group of organizations from the aging and mental health fields

• Comprised of 100 national and state associations, state coalitions, and governmental agencies, e.g., SAMHSA and ACL.

• Co-sponsor events to highlight challenges of mental health and aging

• Identify new approaches to addressing problems.
Webinar Series on “Addressing Disparities in Behavioral Health Care for Older Adults”

• Following the May 20th National Older Adult Mental Health Awareness Day (OAMHD) events, NCMHA developed a plan to collaborate with interested government agencies, private sector groups, and experts to maintain the momentum and recommendations generated from OAMHD.

• A series of webinars during 2019/2020 that target specific topics with a practical focus and accompanying tools/resources to address the needs of older adults with mental health conditions, as well as state/local efforts/best practices.

• A special feature of the webinars will be that the sessions will coincide with monthly, weekly and daily national mental health or aging observances.
Key Objectives of the Webinar Series

- Identify specific approaches that address disparities in behavioral health care for older adults
- Ensure that older adults with mental health and addiction-related conditions are integrated within all MH awareness raising, policy, programmatic and research efforts going forward.
- Raise awareness among primary care, mental health, other health service providers and the aging network about the impact of suicide, opioid use, and interrelated problems, and impact provider practice patterns for older adults.
- Identify specific tools such as geriatric assessment, questions – suicide ideation, firearm presence, opioid use and other screening tools – and detailed guidance.
Webinar Series Roll Out – 2019-2020

January 23, 2020 (12:00 PM EST) – Mental Health Wellness Month
“Solutions to Behavioral Health Workforce Shortages & Lack of Funding”

February 27 (2:00 PM EST) – Eating Disorders and Mental Health Month
“Bridging the Science-Practice Gap: Potential Opportunities for Geriatric Mental Health”

March 26 (3:00 PM EDT) – National Brain Injury Awareness Month
“Traumatic Brain Injury and Mental Illness Among Older Adults: The Problem and New Management Approaches”

April 10, 2020 (12:00 PM EST) – National Public Health Week
“Social Determinants of Mental Health for Older Adults: A New Perspective”
Today’s Webinar

In recognition of Family Caregivers and Alzheimer’s Awareness Month:

“They Invisible Health Care Provider: Family Caregivers of Individuals with Dementia”

Presenter: Stephanie Hughes, MPP, RTI International
The Invisible Health Care Provider: Family Caregivers of Individuals with Dementia

Stephanie Hughes, MPP
RTI International
Overview of today’s session

- About dementia
- Caring for a person with dementia
- Programs and services to support caregivers
  - Education
  - Care consultation/navigation
  - Respite
  - Support groups
  - Legal, financial and care planning
- Professional training
About Dementia
Why are we talking about dementia?

- Over 5 million adults in the U.S. have dementia
- 5th leading cause of death for adults 65+
- As baby boomers age, numbers are growing

Source: CDC
“Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities.”

-NIH National Institute on Aging
Dementia affects:

- Memory
- Language
- Problem Solving
- Concentration
- Visual Perception
- Personality
- Emotions and Mental Health
- Motor Skills
## Types of dementia

<table>
<thead>
<tr>
<th>Type</th>
<th>Percentage</th>
<th>People in the U.S.</th>
<th>Early Symptoms</th>
<th>Causes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Disease</td>
<td>60-80%</td>
<td>5.8 million</td>
<td>Memory loss</td>
<td>Memory loss is the most common early symptom</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>~10-15%</td>
<td>1.4 million</td>
<td>Memory loss</td>
<td>Caused by stroke(s) or other cerebrovascular damage</td>
</tr>
<tr>
<td>Lewy Body Dementia</td>
<td>~20%</td>
<td>1.4 million</td>
<td>Motor symptoms</td>
<td>Typically involves motor symptoms in addition to cognitive and behavioral changes</td>
</tr>
<tr>
<td>Frontotemporal Degeneration</td>
<td>~50,000-60,000</td>
<td>~50,000-60,000</td>
<td>Language or behavior</td>
<td>Younger age of onset</td>
</tr>
</tbody>
</table>

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*Source: Alzheimer’s Association. 2019; Aarsland et al. 2008; Knopman, D. 2019; Schneider, J. et al. 2007*
How do types of dementia differ?

- Early symptoms
- Progression
- Age of onset
- Co-occurring conditions
How are people with dementia cared for?

- 70-80% of people with dementia live in the community
- 3/4 are cared for by family and friends
- Over 16 million people provide informal care

Source: Alzheimer’s Association, 2019
About Caregivers
Caregivers of people living with dementia

- 2/3 are women
- 1/3 are over 65
- More than 1/2 provide 20+ hours of care/week
- 2/3 live with the person with dementia
- Most are spouses, partners or adult children
- Caregivers of people with dementia make up about 1/2 of caregivers for older adults

Source: National Alliance for Caregiving and AARP, 2015; Kasper, Freedman, & Spillman, 2014; Alzheimer’s Association, 2014
What do caregivers help with?

- Bathing
- Managing money
- Coordinating medical care
- Managing behavioral symptoms
- Dressing
- Toileting
- Transportation
- Social support
- Managing other medical conditions
Caregiving across the stages of dementia

Early
- “Care partner”
- Help with managing finances
- Help with organization or planning
- Emotional support

Moderate
- “Caregiver”
- Assist with bathing, dressing, preparing food
- Provide supervision
- Modify communication
- Adapt to changes in behavior and personality

Advanced
- Provide around the clock care
- Assistance with using the bathroom, walking, eating
- Often require paid assistance, either in-home or in a facility

Source: www.DementiaCareCentral.com
Positive aspects of caregiving
Health impact of caring for someone with dementia

- Provide on average 1-4 years more care than for someone with another illness
- Rates of depression are 2x higher than other types of caregiving
- Caregivers who live with the person with dementia tend to experience greater stress and burden
- Compared to non-caregivers: higher medical costs, more doctor visits, and greater medication use

Source: Black et al., 2013; Family Caregiver Alliance, 2016; Zhu et al., 2015; National Alliance for Caregiving and Alzheimer’s Association, 2017
**Social:** Greater isolation

**Financial:** Dementia caregivers report 2x the out-of-pocket health care costs than other disorders

Source: AARP Public Policy Institute, 2017; Alzheimer’s Association, 2019
Impact of caregiving

Work: More than 1/3 take a leave of absence, quit work or reduce to part-time hours

Family obligations: 1/4 care for a parent with dementia and a child under 18

Source: AARP Public Policy Institute, 2017; Alzheimer’s Association, 2019
Challenges related to non-Alzheimer’s dementias

- Delayed diagnosis
- Misdiagnosis
- Shortage of knowledgeable medical professionals
- Lack of information
- Isolation
Services for Caregivers
Evidence-based programs and services

- 44+ specific programs/services shown to be effective
- Non-pharmacological approaches are often more effective than medication
- Multiple components may be beneficial
  - Delivered by a variety of providers
  - In-home, in group setting, via phone, or online

Sources: Maslow, 2012; AARP Public Policy Institute, 2017; Brodaty et al., 2003; Gitlin et al., 2015; Chee et al., 2007; Gitlin & Rose, 2013
Positive outcomes for caregivers

- Coping skills
- Confidence
- Caregiving skills
- Quality of life

- Burden
- Depression
- Reaction to behavioral symptoms

Source: AARP Public Policy Institute, 2017; Hughes et al., 2017
Challenges in getting services to caregivers

- Dissemination
- Geographic variation
- Provider awareness
- Time constraints
- Alternative care for the person with dementia
Types of Supportive Services and Programs
Education

- Dementia basics
- Communication techniques
- Behavior symptom management
- Self-care, stress management
- Safety
- Legal and financial planning
- Community resources
Examples of education programs

- **Savvy Caregiver Program** (Dr. Kenneth Hepburn, Emory University)
  - 12-hour group workshop provided over 6 weeks (Abbreviated and online versions as well)
  - Provides knowledge, skills and attitudes needed to manage dementia caregiving

- **New Ways for Better Days: Tailoring Activities for Persons with Dementia and Caregivers** (Dr. Laura Gitlin, Drexel University)
  - Delivered by occupational therapists through up to 8, 1-hour, one-on-one sessions
  - Trains caregivers on how to incorporate meaningful activities into the daily routine of the person with dementia

- **Behaviors & Alzheimer’s Disease: Are they doing that to annoy us?** (Alzheimer’s Los Angeles)
  - A brief, 1-2 hour group training on understanding changes in behaviors and how to respond
  - Was developed for busy caregivers who may have low literacy levels

- **STAR-Caregivers (STAR-C)** (Dr. Linda Teri, University of Washington)
  - 12 in-home and telephone sessions are delivered over a period of several months
  - Includes dementia basics, behavior management techniques, communication skills, and emphasis on pleasant activities
Education resources

- **Education Resources for Persons Living with Dementia and Family Caregivers** – National Alzheimer’s and Dementia Resource Center
- **Caregiver Tip Sheets** – Alzheimer’s Los Angeles
- **Caregiver Training Videos** – UCLA Health
- **iCareFamily** – National Institute on Aging (series of training videos focused on stress management)
- **Alzheimer’s and Dementia Caregiver Center** – Alzheimer’s Association (website and online training)
- **Educational webinars on FTD** – Association for Frontotemporal Degeneration
- **Educational webinars on LBD** – Lewy Body Dementia Association
Care consultation/care navigation

For the person with dementia:
- Managing multiple conditions
- Transitioning from hospital to home or other facility
- Link between health care and community services

For the caregiver:
- Needs assessment
- Education
- Support
- Navigate services and resources
Examples of care consultation/care navigation programs

- **BRI Care Consultation** – (Benjamin Rose Institute)
  - Trained consultants support people with dementia and caregivers through a series of 10 telephone calls over the course of several months. Challenges and resources are identified, action steps are planned, and the consultant follows up with the clients continually to assess progress and needs.

- **Adult Day Services Plus** (Dr. Laura Gitlin, Drexler University)
  - Augments adult day services with additional education and support for caregivers, including: care management, referral/linkage, education about dementia, situational counseling/emotional support/stress reduction techniques, and skills to manage behavioral symptoms

- **Maximizing Independence at Home (MIND)** (Johns Hopkins University)
  - Care coordinators conduct an in-home assessment and coordinate with a clinical team, providing people with dementia and caregivers with linkage to community-based agencies, resources, and medical and mental health providers.

- **Support Health Activities Resources Education (SHARE)** (Benjamin Rose Institute)
  - Helps families in the early stage of the disease to plan for the future
  - Provided one-on-one over 5 sessions
Care consultation/care navigation resources

- **Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers** – Family Caregiver Alliance
- **Community Based Service Provider Practice Tool** – ACT on Alzheimer’s
- **Collaborative Care Coordination** – Virginia Department for Aging and Rehabilitative Services
Respite

Enables caregivers to:
– Work
– Do errands
– Socialize
– Take a break

May provide person with dementia:
– Engaging activities
– Socialization
Respite delivery

**Where**
- In the home
- Adult day
- Other health or care facility

**How**
- Overnight vs. day
- Emergency vs. ongoing
- Self-directed vs. specified use
Respite resources

- **National Respite Locator** – ARCH National Respite Network
- **Respite Care for Dementia Caregivers** – Dementia Care Central
- **Veterans Health Administration**
- Local Alzheimer’s organizations
- Local Area Agency on Aging
Support groups

Where
- In person
- Online

Who
- Caregivers, persons with dementia, or both
- Early onset
- Disease stage
- Type of dementia
- Bereavement

Frequency
- Weekly
- Monthly
Support group resources

- **Alzheimer’s Association**
  - Online community
  - Local support groups

- **Alzheimer’s Foundation of America**
  - Telephone support groups

- **Lewy Body Dementia Association**
  - [Online communities](#)
  - [Local support groups](#)

- **The Association for Frontotemporal Degeneration**
  - [Online and telephone support communities](#)
  - [Local support groups](#)
  - [Support and resources for kids and teens](#)

- **Other local Alzheimer’s organizations**
Legal, financial and care planning

- Peace of mind for person with dementia and caregiver
- Better quality of life for person with dementia
- Preserve financial resources
Legal, financial and care planning resources

- **Living with Dementia: Advance Planning Guides for Persons with Dementia and Caregivers** – National Alzheimer’s and Dementia Resource Center

- **Managing Someone Else’s Money guides** – Consumer Financial Protection Bureau

- **Financial and Legal Planning for Caregivers** – Alzheimer’s Association

- **Conversation Starter Kit for Families and Loved Ones of People with Alzheimer’s Disease or Other Forms of Dementia** – The Conversation Project
Learn more: training resources for professionals

- **Training Resource Compendium for Dementia Care Providers and Volunteers** – National Alzheimer’s and Dementia Resource Center

- **Alzheimer’s Disease and Related Dementias Curriculum**, *Health Resources Services Administration*

- **Mental Health and Aging Training Initiative webinar series**, *Virginia Geriatric Mental Health Partnership*

- **Dementia Curriculum**, *Act on Alzheimer’s Collaborative, Minnesota*

- **Creating Dementia Capable Health Care Systems**, *Alzheimer’s Greater Los Angeles*

- **Dementia Capability webinars**, *Rosalynn Carter Institute*

- **Free eLearning Workshops**, *Alzheimer’s Association*
More Information

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Any questions?