Bree Collaborative | Alzheimer's and Other Dementias Revision
June 8th 2026| 2:30-4PM PST
Hybrid

MEMBERS PRESENT

Kris Rhoads, PhD, UW
Carla Ainsworth, MD, KP
Allyson Schrier
Lynne Korte, MPH, DSHS
Maureen Schmitter-Edgecombe, PhD, WSU
Barak Gaster, MD, UW
Carroll Haymon, MD, Providence Swedish
Jamie Teuteberg, MS, HCA
Emily Trittschuh, PhD, VA
Marci Getz, MPH, DOH
Rich Furlong, MD, VMFH
Nancy Isenberg, MD, MPH, Swedish Neuroscience Institute
Vicki McNeally, PhD, MN, RN, Washington Health Care Association
Katina Rue, DO, Team Health
Laura Cepoi, MA, Olympic Area Agency on Aging
Michelle Hamilton, MDO, MBA, Molina

STAFF AND MEMBERS OF THE PUBLIC

Emily Nudelman, DNP, RN, Bree Collaborative
Karie Nicholas, MA, GDip, Bree Collaborative
Alice Allen-Redfern, LICSW, Nolia Health
Lama Sibai, PsyD, MA, Nolia Health

INTRODUCTIONS

Emily welcomed everyone to the meeting and reviewed the agenda. Minutes were reviewed and adopted. Emily provided brief updates to the workplan, including asynchronous literature gathering, uploading to our SharePoint website, (password: BreeDementia2026) and guideline review.

Action: Motion to approve the May minutes
Outcome: May minutes approved

PRESENTATION: NOLIA HEALTH – TRANSFORMING FAMILY CAREGIVING INTO A PILLAR OF THE HEALTHCARE SYSTEM

Emily invited Alice Allen-Redfern forward to present the care model from Nolia health, a participant of the GUIDE model.

- Team includes:
  - Nurse practitioners, neuropsychology, therapists, and care navigators
- Programs include:
  - GUIDE
  - Chronic care management
  - Principal illness navigation
  - Cognitive care
  - Caregiver support groups
  - Caregiver education workshops
  - Advance care planning
- Our philosophy
  - Support the caregiver, support the patient
- Why it requires a family-centered approach

- Dementia is not an individual condition – it is a family condition
- Family caregivers provide the majority of dementia care in the United States
- Common caregiver challenges include:
  - Emotional distress, anxiety, depression
  - Navigating fragmented healthcare and long-term care systems
  - Financial strain
  - Social isolation
  - Complex decision-making
  - Managing behavioral and psychological symptoms of dementia
- Supporting studies:
  - Family-Centered Primary Care for Older Adults with Cognitive Impairment | Contemporary Family Therapy | Springer Nature Link
  - A scoping review of family-centered interventions in dementia care - Meena Ramachandran, Kshama Bangera, Sebestina Anita Dsouza, Patricia Belchior, 2023
- Informed by care ecosystem UCSF care model
  - Many of the core components of GUIDE rooted in UCSF care ecosystem
  - Addresses critical gap in dementia care: while dementia affects the entire family system, healthcare traditionally focused almost exclusively on the patient
  - Core components:
    - Dedicated care team navigator
    - Caregiver education and coaching
    - Interdisciplinary team support
    - Behavioral symptom management
    - Medication review and reconciliation
    - Advance care planning
    - Community resource navigation
    - Respite for the caregiver
    - Longitudinal support over time
  - Research demonstrated
    - Reduced caregiver burden and depression
    - Improved QOL
    - Reduced ED utilization
    - Reduced potentially inappropriate medication use
    - Lower healthcare costs compared to usual care
- Standardized Medicare benefit that can be delivered across the country

- What we measure
  - Caregiver outcomes
    - Zarit burden survey (caregiver stress)
    - Promis global health (QOL)
    - SDOH (PRAPARE)
    - Caregiver engagement and participation
  - Clinical and operational outcomes
    - Care plan completion
    - Community resource utilization
    - Medication reconciliation
    - Service engagement

        - Healthcare utilization
    - What families report
        - Reduced stress and overwhelm
        - Greater confidence managing dementia
        - Feeling less isolated
        - Better understanding of what to expect
        - Increased preparedness for future decisions
- Key takeaway: proactive care navigation and caregiver support may reduce crisis-driven healthcare utilization while improving the experience of patients and families
- GUIDE strengths and challenges
    - Strengths
        - Dedicate care navigation
        - Comprehensive assessment and individualized care plans
        - Caregiver education and training
        - Interdisciplinary dementia care
        - Medication review and reconciliation
        - Annual respite benefit for moderate- and high-needs caregivers
        - Longitudinal support across the disease trajectory
        - Cost-sharing is waived, no copay or bills for GUIDE services
    - Families are consistently highlighting importance of respite care; elimination of financial barriers
    - Challenges
        - Administrative complexity
        - Workforce and implementation demands
        - Eligibility restrictions
        - Difficulty maintaining support when individuals transition into residential care settings
        - Restrictions about ability to provide GUIDE in long term care settings

Discussion

- Virtual only, and only in English?
    - Able to offer support through interpreter services and languages on staff as well; all services are virtual
- Can you expand on the long term care ruling? Are they excluding facility living more broadly?
    - The wording is that residential care community – affects assisted living, adult family homes, memory care
- What is the availability for urgent care needs?
    - Coordinate with other care team members
- How often are families using respite benefits?
    - Often, and it can happen pretty quickly, quick turnaround to make someone eligible and get them respite care pretty immediately
    - Rural areas often have no respite providers in the area
    - Some counties are being told that there are no opportunity for GUIDE in their area due to no respite provider

PRESENT& DISCUSS: ONGOING CARE, SUPPORT & MANAGEMENT

Kris Rhoads transitioned the workgroup to begin reviewing the ongoing care, support and management guidelines for all report audiences. Emily Nudelmen reviewed the guidelines in real-time with the group and the following changes were made in green:

Persons living with cognitive impairment and their families

Talk with your care team about how to maintain quality of life and what quality of life means to you and your family. This can include:

- Progression of cognitive impairment
- Managing other conditions that you might have
- Driving status and safety; Home safety and risk of falls
- Feeling down or depressed
- Confusion, agitation, aggression, and/or wandering
- Sleep quality and sleep disturbance
- Managing medications
- Care partner stress and fatigue; ability of your care partner/family to meet your care needs now and in the future
- When and whether palliative care or hospice might be appropriate
- ~~Any other concerns~~

Discussion

- Is the intent of this section for people with cognitive impairment to view it?
    - In 2017 part of the intention was to highlight what providers should know what they might be asked about,
    - Need to focus on access and readability, this is too high a reading level
    - Maybe we create a handout/one-pager
    - Want to keep an audience directed at care teams rather than people living with Alzheimer's and Other Dementias -= therefore what's this list for?
    - Could be used as a list of things that care teams should be prepared to answer these questions
    - **Ultimately landed on:** Keep these guidelines in, but need to adjust with focus on access and readability
- This section is helpful for caregivers who may see some signs of stress showing up in their blood work and biomarker tests –
    - Need to provide some empowerment to the family that the person can do well if and when these things are managed

Primary Care

1. Incorporate the dementia diagnosis and consideration for the patient's cognitive function into shared decision making for routine medical care (e.g., avoiding complicated sliding scale insulin routines for those managing diabetes)
2. Identify the patient's goals of care and work to maximize function that meets patient and family needs.
3. Identify and address conditions that may worsen symptoms (e.g., depression, diabetes, hearing loss)
4. Consistently include the patient and family or other caregivers as part of the care team. This means proactively asking about, routinely reassessing, and centering care plans around their needs, preferences, and capacity

5. Support caregivers and assess caregiver distress, fatigue, capacity, knowledge, and skills as a core component of each visit.
6. Offer dementia care management services (e.g., home health, geriatric care managers, enhanced outpatient management) to patients and caregivers who have been determined to be high-risk
7. ~~Offer appropriate interventions depending on patient-specific factors.~~
8. Educate family about the diagnosis and available treatment including the natural progression of dementia.
9. Ask about and discuss neuropsychiatric symptoms (e.g., agitation, psychosis) and management strategies using a shared-decision making approach.

Discussion

- What does "offer appropriate interventions" mean?
    - Maybe reflective of amyloid PET scans or other things dependent on BBM
- What does the first bullet mean?
    - Take into consideration the dementia diagnosis when managing other medical care (e.g., diabetes diagnosis)
    - Dementia diagnosis is an organizing principle for how other care is delivered
        - Example: do not add complicated insulin sliding scale for person with cognitive impairment
- Awareness early on about care management services could prevent a situation to become high risk?
    - General agreement that this should be offered more broadly – difficult to determine who is high risk
- Need to reorder things to offer the most benefit at the top, such as educate family about diagnosis and available treatment including natural progression of dementia
    - Need to make this tighter in general – PC has a lot to balance, and they are not able to digest the long list of guidelines

<u>Health Plan</u>

1. Increase member awareness of how to maintain brain health across the life-course, age-related changes in memory versus the warning signs of dementia, and the benefits of timely diagnosis of Mild Cognitive Impairment (MCI), Alzheimer's disease, and other dementias.
2. When initial diagnosis of dementia is identified on a claim:
    1. Route automatically to care manager/navigator team
3. Cover hearing and vision aids with minimal to no cost-share
4. Flag members who may be demonstrating a high risk for cognitive impairment and alert assigned primary care provider. Consider the following as potential indicators of high risk:
    1. Increased ER utilization; fall-related events; etc?
5. Explore opportunities to allow billing for cognitive assessment delivered by a trained non-physician in primary care
6. Require cognitive assessment evaluation as a prior authorization requirement for coverage of blood-based biomarkers
7. Measure patient and family satisfaction with dementia care with use of a survey tool similar to that used by hospice agencies .

8. Develop inclusive and comprehensive benefits for patients with Alzheimer's disease or other dementia allowing them to receive care consistent with their wishes and goals even if not eligible for hospice (e.g., palliative care).
9. Facilitate information sharing and patient and family outreach during transitions between health care facilities and times of crisis

Discussion

- How much of this are health plans already doing?
    - Not sure how much they are doing, they do some health promotion type things but not sure if its based on brain health
- Would love to see health plans when a diagnosis is on a claim that it automatically flags case manager/navigator/etc. offer connection to resources similar to first claim diagnosis is pregnancy
    - Could be dementia roadmap, 1-800 number for alzheimer's association, and connection to their triple A's (area agency on aging)
- Any attempt to make the health plan the org to flag high risk patients is not going to be well-received by primary care, and hard to plug in. maybe move #3 to health system perspective, not health plan perspective
    - Health plans are the ones that have the data, that is the problem
- Health plans could do a better job of supporting preventive care
    - Could be better at holding health plans accountable for identifying people who might be a greater risk and intervening – maybe they do this in partnership with EHR/health system?
    - Health plans are motivated to get people to a diagnosis too, so wonder about getting health plan to interface with the member instead of with the health system?

Employers

1. Promote employee wellness by increasing awareness of how to maintain brain health across the life-course, about the difference between age-related changes in memory and the warning signs of dementia, and about the benefits of timely diagnosis of Mild Cognitive Impairment (MCI), Alzheimer's disease, and other dementias.
2. Incorporate family caregiver supports for employees into employee assistance programs, including medical respite models.
3. Make employees aware of:
    1. WA Family Caregiver Support Programs (DSHS)
    2. WA Paid Family Medical Leave Benefit

State Agencies

HCA

1. Integrate incentives for quality improvement in care for older adults aligned with age-friendly health systems
    1. Ask about and align the care plan with what matters most to them
    2. Review, avoid, and if possible, deprescribe, high-risk medications
    3. Screen for delirium, cognitive impairment, and depression
    4. Screen for mobility limitations and ensure early, frequent and safe mobility

2. Test implementation of payment models for comprehensive dementia care especially for underserved communities

DOH

1. Nothing yet – follow up with Marci from DOH

Discussion

- Employers:
    - Become an age-friendly employer:
        - Include information for employers to support people who might be still working and living with cognitive decline & the Brain Health At Work™ | Alzheimer's Association opportunity to create more awareness
        - Need to improve EAP provider awareness of dementia
            - Add specific language around employer sponsored support groups for those caring for family members with dementia
- HCA
    - State level certification for "brain health and dementia care experts" in primary care
        - Have been part of conversations around this a lot
    - Need to encourage geriatric emergency departments in addition to age-friendly health systems
    - Not sure about in the current atmosphere we would get any movement for VBP
    - Adding to contract language for MCO, think about contracts and need to address care coordination
    - From the dementia state plan: test implementation of payment models for comprehensive dementia care especially for underserved communities

PUBLIC COMMENT AND GOOD OF THE ORDER

Emily invited Karie Nicholas to share more about the evaluation subcommittee and ask for volunteers. The subcommittee will start meeting between June – December, email her at knicholas@qualityhealth.org if interested.

Kris invited final comments or public comments, then thanked all for attending. **There was one question about how these guidelines are disseminated to the broader community**: we rely on HCA, our Bree members, and partnership with all organizations in the community through our networks to promote and disseminate our reports and guidelines. For example, we include our information in other newsletters where applicable (WSHA, WSMA, etc.)

The workgroup's next meeting will be on Monday, July 20th from 2:30-4PM.