MEETING THE CHALLENGE OF CARING FOR PERSONS LIVING WITH DEMENTIA AND THEIR CARE PARTNERS AND CAREGIVERS

A WAY FORWARD

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National Institute on Aging's Charge to the Committee

Assess the available evidence on care interventions for people with dementia and their caregivers, based predominantly on an AHRQ systematic review

Inform decision making about disseminating and implementing care interventions on a broad scale

Identify research gaps

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Study Model

Phase I: National Academies committee informed the design of an AHRQ systematic review

Phase 2: National Academies committee used the AHRQ systematic review as the primary source of evidence for its report, along with supplemental evidence sources

- Committee held a public workshop and other public sessions to receive information
- An advisory group of persons living with dementia and care partners/caregivers provided input.

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Moving Toward Better Dementia Care

Living Well With Dementia

- Persons living with dementia desire support in leading meaningful and rewarding lives, maintaining independence and agency, enjoying activities of interest, sustaining social relationships, and connecting to familiar environments and communities.

- To live well with dementia, people need care, services, and supports that reflect their values and preferences, build on their strengths and abilities, promote well-being, and address needs that evolve as cognitive impairment deepens.

An Urgent Need

- Between 3.7 and 5.8 million Americans are living with dementia.
- 21.6 million Americans are providing care to someone living with dementia.
- The needs of many persons living with dementia and their care partners and caregivers are not being met.
  - In particular, there are deep and persistent inequities with respect to racial and ethnic minorities.
- Persons living with dementia, care partners, and caregivers are eager for interventions that will address their needs and preferences.

Guiding Principles and Core Components of Dementia Care, Services, and Supports

Even though the committee was disappointed by the AHRQ review conclusions regarding the shortage of high-strength evidence, this **does not call into question fundamental aspects of high-quality dementia care, services, and supports**. Clearly, additional research is needed on specific interventions.

In the meantime, organizations, agencies, communities, and individuals can **use the guiding principles and the core components of care** (as shown on the next slide) **to guide actions** toward improving dementia care and addressing the urgent need.

Guiding Principles

Person-centeredness

Promotion of well-being

Respect and dignity

Justice

Racial, ethnic, sexual, cultural, and linguistic inclusivity

Accessibility and affordability

Core Components

Detection and diagnosis

Information and education

Medical management

Support in activities of daily living

Support for care partners and caregivers

Communication and collaboration

Coordination of medical care, long-term services and supports, and community-based services and supports

Supportive and safe environment

Advance care planning and end-of-life care

Please see the report for sources.

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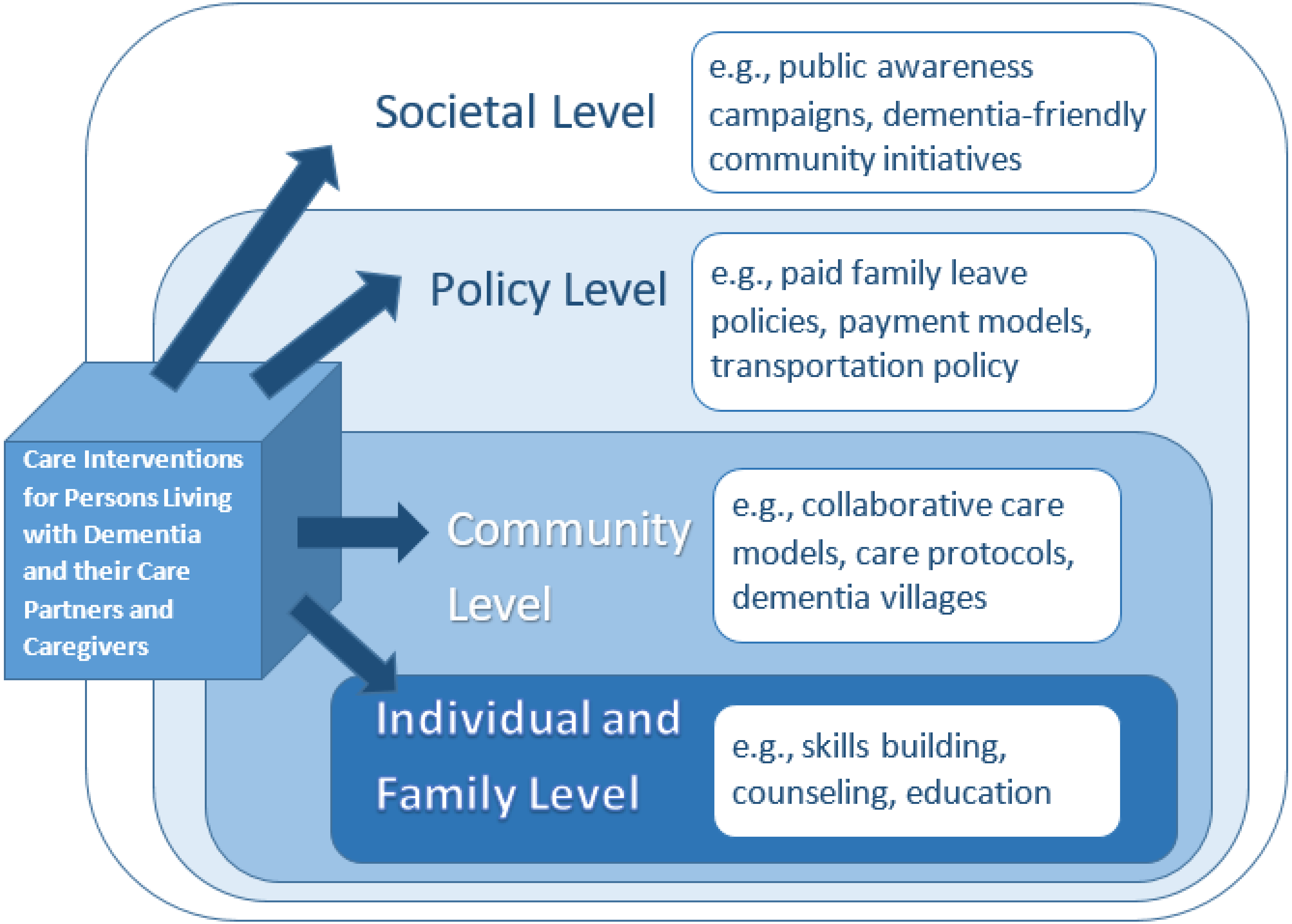
Assessing Evidence and Making Decisions in Complex Systems

Framework for Care Interventions



Care Interventions for Persons Living with Dementia and their Care Partners and Caregivers

Societal Level

e.g., public awareness campaigns, dementia-friendly community initiatives

Policy Level

e.g., paid family leave policies, payment models, transportation policy

Community Level

e.g., collaborative care models, care protocols, dementia villages

Individual and Family Level

e.g., skills building, counseling, education

Complexity of Systems

Dementia care interventions are complex as a result of

- the **multiple levels** at which they are implemented,
- **interactions** among those levels,
- the **diversity of persons** living with dementia, care partners, and caregivers, and
- the **complexity of the interventions** themselves.

This complexity presents challenges to the evaluation of interventions, and limited the ability of the AHRQ systematic review to draw conclusions for many of the interventions considered.

Making Decisions about Implementation

- The collection and publication of evidence on the implementation and dissemination of interventions is insufficient.
- Interventions that have demonstrated efficacy need to be tailored to local settings and populations.
- Monitoring and evaluation are important to assess the translation of interventions to real world settings, and help guide adjustments.
- Pragmatic trials and adaptations may show that some interventions are not effective in real-world settings or in certain contexts.
- Different stakeholders use different criteria to inform their decisions on the implementation of dementia care interventions.

Interventions Ready for Implementation with Evaluation

Findings from the AHRQ Systematic Review

The AHRQ review identified no interventions that met its criteria for high-strength or moderate evidence of benefit.

The AHRQ review concluded that **two intervention categories were supported by low-strength evidence** of benefit:

- Collaborative Care Models
  - may improve quality of life for persons living with dementia
  - may improve system-level markers, including guideline-based quality indicators and reduction in emergency department visits
- Discrete adaptations of REACH II improved care partner and caregiver depression at 6 months

Approach to Assessing the Evidence on Readiness for Broad Dissemination and Implementation

In addition to effectiveness, the committee compiled available evidence on other factors that are important for decision making about implementation: **equity, acceptability, feasibility, and resources**.

To complement the AHRQ review conclusions, the committee considered available evidence on these two types of interventions derived from:

- Reference mining of included studies
- Reviewing studies in AHRQ review that did not meet inclusion criteria
- PubMed and hand searches
- Best Practice Caregiving database
- Center for Medicare and Medicaid Innovation evaluations

Collaborative Care Models

The collaborative care interventions evaluated by the AHRQ review **share multiple components**, including coordination of services, development of care plans, case tracking, and provider collaboration.

These models operationalize many of the core components of care discussed earlier.

Collaborative Care Models: Effectiveness

The AHRQ review found sufficient evidence to draw conclusions about low-strength evidence of benefit for:

- Persons living with dementia: quality of life, quality indicators, and emergency room visits.

Individual studies in the AHRQ analytic set also reported benefit for the following outcomes, although the evidence was not sufficient to reach conclusions on effectiveness for these outcomes, generally due to inconsistent findings across studies.

- Persons living with dementia: neuropsychiatric symptoms and nursing home placement
- Care partners and caregivers: strain, depression, and quality measures.

Collaborative Care Models: Other Factors

- Collaborative care models have been studied in multiple and diverse populations and with individuals along the spectrum of disease severity.
- They often leverage existing resources and partnerships.
- While these interventions have been disseminated and used in relatively limited ways to date, some evidence related to acceptability, feasibility, and resources is available to inform implementation.

REACH II and Its Adaptations

REACH II is a multicomponent intervention for care partners and caregivers.

REACH II and its adaptations share seven common components: problem solving, skills training, stress management, support groups, provision of information, didactic instruction, and role playing.

REACH II and Its Adaptations: Effectiveness

The AHRQ review found low strength evidence that REACH II and its adaptations reduce **caregiver depression**.

The AHRQ review identified a reduction in **caregiver strain** in some studies included in the analytic set, but ultimately the evidence was insufficient to draw a conclusion.

REACH II and its adaptations have been implemented and evaluated in **a wide range of real world settings**, but **many of these studies did not meet the AHRQ review inclusion criteria**, in many cases because they used an ineligible study design such as a single pre–posttest. Some of these studies reported benefits on such outcomes as

- Reductions in caregiver strain or stress, caregiver depression, challenging behaviors, caregiver frustration or bother, and physical symptoms.
- Improvements in such outcomes as self-reported social support, self-reported caregiver health, caregiver reactions to challenging behaviors, positive aspects of caregiving, and safety of persons living with dementia.

REACH II and Its Adaptations: Other Factors

- REACH II has progressed from efficacy testing to implementation in real world care settings.
- REACH II has been studied in and adapted for diverse populations to a greater extent than is usual in the field. It has been delivered in racially/ethnically, linguistically, geographically, and socioeconomically diverse populations.
- It is provided by many existing organizations (e.g., Veterans Affairs, local Alzheimer’s Association chapters).
- Reported data offer a moderate amount of evidence regarding resource requirements.

Conclusions on REACH II and Collaborative Care Models

The state of the evidence base for these two intervention types as assessed by the AHRQ review complicates making recommendations for a path forward.

The committee’s recommendations are based on the following argument:

1. Given the inherent challenges and complexities, **the fact that these two interventions produced low-strength evidence of effectiveness is important**.
2. There is a **notable trend in benefits** across multiple outcomes beyond those for which the AHRQ review was able to draw a conclusion, and the consistency of evidence of benefit across sources of evidence is encouraging.
3. There is a moderate amount of evidence to inform implementation on such factors as **equity, acceptability, feasibility, and resources**. Particularly important, these interventions have been studied in diverse populations, although additional evidence is needed to expand understanding of their use in all populations.

Conclusions on REACH II and Collaborative Care Models (cont.)

Taken together, these considerations led the committee to conclude that the evidence is **sufficient to justify implementation** of these two types of interventions in a broad spectrum of community settings, **with evaluation** conducted to continue expanding the evidence base to inform future implementation.

The committee believes that **this approach is likely to bring greater gains and better inform real-world implementation** relative to focusing on additional large RCTs aimed at generating moderate- or high-strength evidence in a future systematic review before any further dissemination can be supported.

Recommendation 1: Implement and evaluate outcomes for collaborative care models in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information sharing.

Along with adding to the current evidence for effectiveness, these efforts should include **examining key factors that are important for determining whether and how to implement an intervention**, such as identifying workforce and space needs, testing payment models and integration into workflow, and ensuring adaptations for different populations (e.g., racial/ethnic groups) and settings (e.g., rural areas).

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Recommendation 1 *(continued)*: Implement and evaluate outcomes for collaborative care models in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information

Specifically, to advance these efforts:

- The **Centers for Medicare & Medicaid Services** should explore the value of collaborative care models offered as a benefit through Medicare Advantage programs and alternative payment models and for fee-for-service beneficiaries to build the infrastructure, train the workforce, and redesign the workflows that would facilitate the adoption, monitoring, and evaluation of these programs.
- **State Medicaid programs** serving persons living with dementia and dual-eligible beneficiaries should encourage participating health systems, systems that provide long-term services and supports, and managed care organizations to provide collaborative care for persons living with dementia. This care could be included in a dementia-focused quality metric.

Recommendation 1 *(continued)*: Implement and evaluate outcomes for collaborative care models in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information

- The **National Institute on Aging, HHS's Office of the Assistant Secretary for Planning and Evaluation, the Agency for Healthcare Research and Quality, and the Administration for Community Living** should support research and stakeholder engagement focused on collaborative care models to aid in scaling and sustaining the models; identifying monitoring and evaluation standards; developing monitoring and evaluation plans; and sharing information about key findings, lessons learned, and promising practices.
- **Health care systems, including those in the Department of Veterans Affairs,** should support infrastructure that would facilitate the collaboration of providers of primary care, mental health and other specialty care, and long-term services and supports within the health care system and with local home-based community services and supports agencies in implementing collaborative care models to improve the well-being of people living with dementia and their care partners and caregivers.

Recommendation 2: Implement and evaluate outcomes for REACH II and its adaptions in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information sharing.

Along with adding to the current evidence for effectiveness, these efforts should include **examining key factors that are important for determining whether and how to implement an intervention,** such as identifying workforce and space needs, testing payment models and integration into workflow, and ensuring adaptations for different populations (e.g., racial/ethnic groups) and settings (e.g., rural areas).

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Recommendation 2 *(continued)*: Implement and evaluate outcomes for REACH II and its adaptions in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information sharing.

Specifically, to advance these efforts:

- The **Centers for Disease Control and Prevention and the Administration for Community Living** should incorporate REACH II and its adaptations into its efforts to support evidence-based dementia programs at state and local public health departments in concert with community organizations.
- The **Centers for Medicare & Medicaid Services** should explore the value of REACH II and its adaptations offered as a benefit through Medicare Advantage programs and alternative payment models and for fee-for-service beneficiaries to build the infrastructure, train the workforce, and redesign the workflows that would facilitate the adoption, monitoring, and evaluation of these programs.

Recommendation 2 *(continued)*: Implement and evaluate outcomes for REACH II and its adaptions in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information sharing.

- **State Medicaid programs** serving persons living with dementia and dual-eligible beneficiaries should encourage participating health systems, systems that provide long-term services and supports, and managed care organizations to provide REACH II and its adaptations for care partners and caregivers. This care could be included in a dementia-focused quality metric.
- The **National Institute on Aging, HHS's Office of the Assistant Secretary for Planning and Evaluation, the Agency for Healthcare Research and Quality, and the Administration for Community Living** should support research and stakeholder engagement focused on REACH II and its adaptations to aid in scaling and sustaining the model; identifying monitoring and evaluation standards; developing monitoring and evaluation plans; and sharing information about key findings, lessons learned, and promising practices.

Recommendation 2 *(continued)*: Implement and evaluate outcomes for REACH II and its adaptions in multiple and varied real-world settings under appropriate conditions for monitoring, quality improvement, and information sharing.

- The **Department of Veterans Affairs** should participate in monitoring, quality improvement, and information-sharing initiatives to enable other entities to learn from its implementation of this intervention.
- **Health care systems** should support infrastructure that would facilitate the collaboration of providers of primary care, mental health and other specialty care, and long-term services and supports within the health care system and with local home-based community services and supports agencies in implementing REACH II and its adaptations to improve the well-being of people living with dementia and their care partners and caregivers.

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Improving and Expanding the Evidence Base: Gaps and Opportunities

Evidence on Other Interventions

- Beyond collaborative care models and REACH II, the AHRQ review found **insufficient evidence** to support conclusions about benefit for all other interventions.
- This **does not imply these interventions are ineffective**. Instead, it reflects the high uncertainty given the limitations of the evidence base and the approach used in the AHRQ review to support conclusions on readiness for broad dissemination and implementation.

Approach to Identifying Gaps and Opportunities in the Evidence Base

- Identify interventions with signal of benefit
  - Based on the observation of benefit for a given outcome in multiple independent RCTs evaluating the same (or a similar) intervention, even if the overall body of evidence was mixed for that outcome.
- Stakeholder input from information-gathering meetings (e.g., persons living with dementia, care partners and caregivers, care systems)
- Best Practice Caregiving database
- National Research Summits on Care, Services, and Supports for Persons with Dementia and Their Caregivers

Gaps and Opportunities

- The evidence base for dementia care interventions appears to be biased toward those targeting the individual level. There is a **lack of interventions targeting community, policy, and societal levels**.
- Interventions targeting **direct care workers** are understudied.
- The evidence **fails to consider the full range of diverse populations** that may benefit from the intervention (e.g., racial/ethnic groups, LGBTQ individuals, rural areas, tribal populations).

Gaps and Opportunities (cont.)

- For some intervention categories, there is insufficient evidence due to **inherent complexity and heterogeneity**. Even though multiple RCTs may show a benefit, little is known regarding which interventions are likely to be effective for persons living with dementia, care partners, and caregivers experiencing different stages of disease progression and how they should optimally be implemented.
  - Examples include exercise, music, psychosocial interventions, and cognitive interventions.

- Significant gaps remain in the evidence base for many interventions evaluated in the AHRQ systematic review due to **lack of high quality evidence** (e.g., too small or too short studies).
  - Examples include late-stage care interventions, respite care, social support, training and support for direct care workers.

A Blueprint for Future Research

Recommendation 3: Use strong, pragmatic, and informative methodologies.

When requesting applications and identifying funding priorities for research on care interventions for persons living with dementia and their care partners and caregivers, the National Institute on Aging and other interested organizations should prioritize strong, pragmatic, and informative methodologies that take account of this complex domain, including studies that

- ensure a balanced portfolio of **short- and longer-term studies with sufficient sample size**;
- use a **harmonized core of outcomes and a taxonomy** of interventions to enable pooling of study findings;
- focus on **outcomes of greatest priority to persons living with dementia and their care partners and caregivers**, including intended and unintended benefits and harms, across the continuum of early- through late-stage dementia;
- include **qualitative methods** in studies that have quantitative outcomes;
- use **observational study methods** to complement randomized trials; and
- commit to **comprehensive study reporting** to enable improving and better understanding fidelity, studying context effects, and learning from negative results and unsuccessful methodological approaches.

Recommendation 4: Prioritize inclusive research.

When funding research on care interventions for persons living with dementia and their care partners and caregivers, the National Institutes of Health (NIH) and other interested organizations should prioritize research that promotes equity, diversity, and inclusion across the full range of populations and communities affected by dementia through studies that

- are conducted by **broadly inclusive research teams**;
- **include racially, ethnically, culturally, linguistically, sexually, and socioeconomically diverse participants** by requiring adherence to the NIH Revitalization Act of 1993, and assess disparities in access and outcomes; and
- use **study designs that support inclusivity**.

Recommendation 5: Assess real-world effectiveness.

When funding research on care interventions for persons living with dementia, care partners, and caregivers, the National Institutes of Health, the Agency for Healthcare Research and Quality, the Centers for Medicare & Medicaid Services, the Administration for Community Living, and other interested organizations should support research capable of providing the **evidence that will ultimately be needed to make inclusive decisions and implement interventions in the real world**, including studies that, to the extent possible,

- improve the assessment of individual-level interventions by leveraging **complementary study methodologies**;
- expand the focus on **community/policy-level interventions** using a broad set of research methodologies; and
- address key factors (e.g., space, human resources, work redesign, and adaptations) that need to be taken into account to **assess the real-world effectiveness** of these interventions.

Final Thoughts

- Providing collaborative care interventions and REACH II to those who could benefit would represent real progress, ***however***
- There is an urgent need for a more robust and useful evidence base.
- Other interventions, especially those that have shown signals of benefit, should continue to be developed and evaluated.
- There is an opportunity to implement new methods and approaches in the field, including through engaging early career researchers, in building this more robust, useful, and inclusive evidence base that will support the well-being of persons living with dementia and their care partners and caregivers.

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Read the report: http://bit.ly/dementiacarestudy

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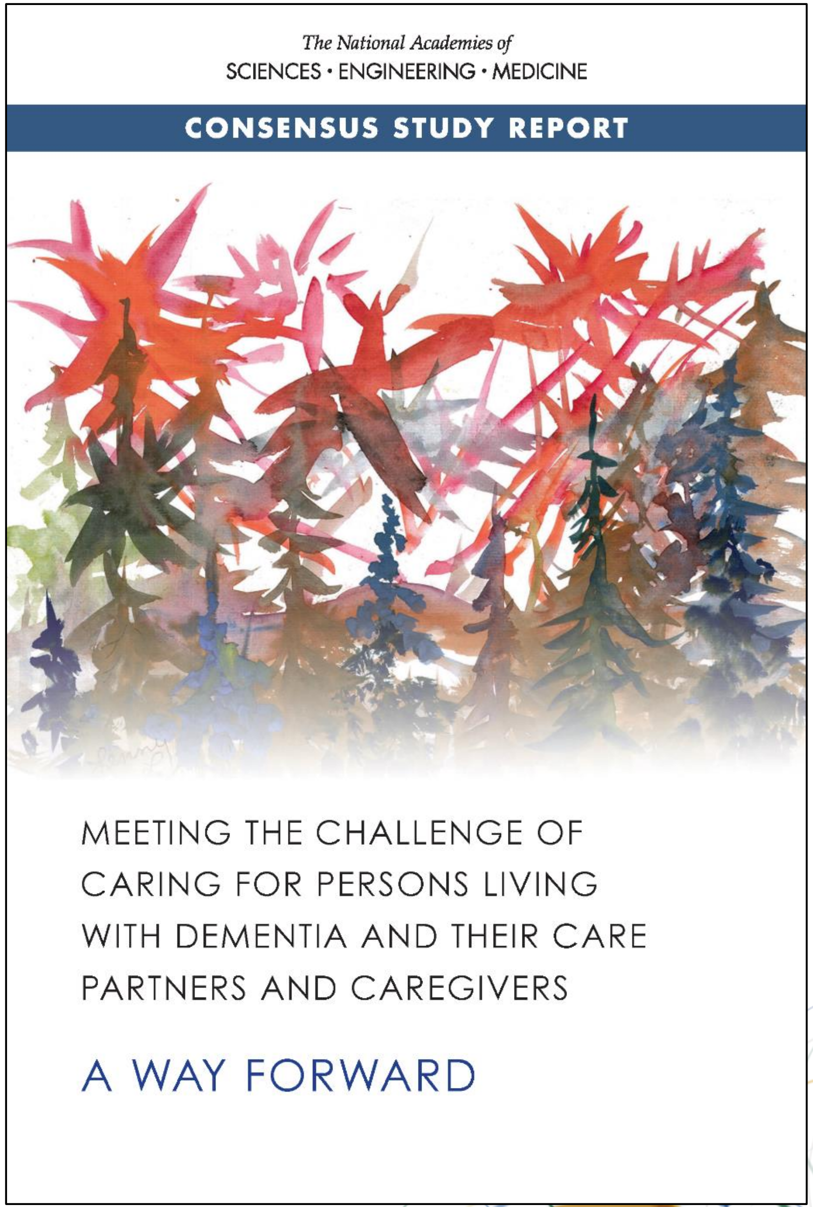

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CONSENSUS STUDY REPORT

MEETING THE CHALLENGE OF CARING FOR PERSONS LIVING WITH DEMENTIA AND THEIR CARE PARTNERS AND CAREGIVERS

A WAY FORWARD