Expanding the Dementia Friendship Circle: A Multi-Sector Priority

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on Early Detection of Dementia

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Disclosures

Current Support:

- National Institutes of Health
- Centers for Disease Control and Prevention

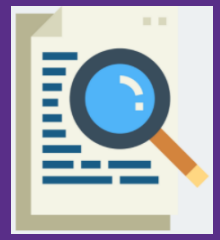
No conflicts of interest to report

BOLD Public Health Center of Excellence on Early Detection of Dementia

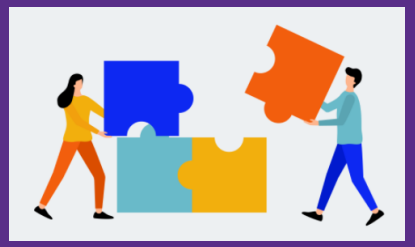
VISION: Quality healthcare and lasting well-being for all older adults and their care partners starts with early detection.

WHO WE ARE: A national resource for driving evidence-based public health strategies for early detection of dementia.

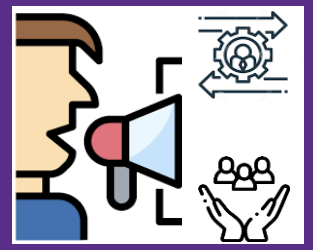
MISSION: To increase early detection of dementia across populations.



Disseminate ways to improve detection



Co-create solutions with national partners



Promote change within stakeholder organizations nationwide

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Getting clear on what we mean

Dementia

- Decline in cognitive functioning serious enough to impair everyday function
- Individuals *may or may not* be aware of how they are functioning
- Close family and friends may 'fill in the gaps'; can take years before they can see a clear pattern

Other Categories of Impairment

- Subjective cognitive decline (SCD): the sense that one's mind is not working as well as it used to, but cognitive performance is in the normal range. SCD can be a warning sign of future dementia – if so, delay to progression can be very long.
- Mild cognitive impairment: decline in cognitive functioning with little or no impact on everyday life. May progress to dementia over time, but doesn't always.

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Dementia: A common sense definition

- A decline in cognitive abilities severe enough to affect everyday function – especially memory, understanding, planning, decision-making, self-and social awareness
- Caused by brain disease (neurodegeneration), systemic diseases, or injury
- The single most disabling condition of older people
- Often a “silent partner” in health care and community settings
- Can be present for several years before it’s recognized

Confusion, muddled thoughts, disorientation

Poor judgement/ decisions e.g., about driving or money

Trouble communicating or finding words

Symptoms of dementia vary by person, by cause, and by severity,. These are common.

Trouble remembering recent events and conversations; trouble planning ahead

Unpredictable behavior

Emotional volatility

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Why early detection of dementia matters

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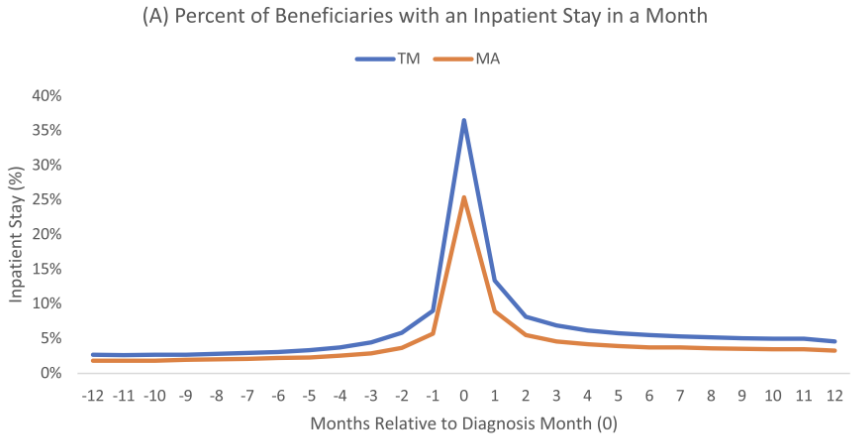
Dementia diagnosis mostly happens as a result of a crisis – often a medical one



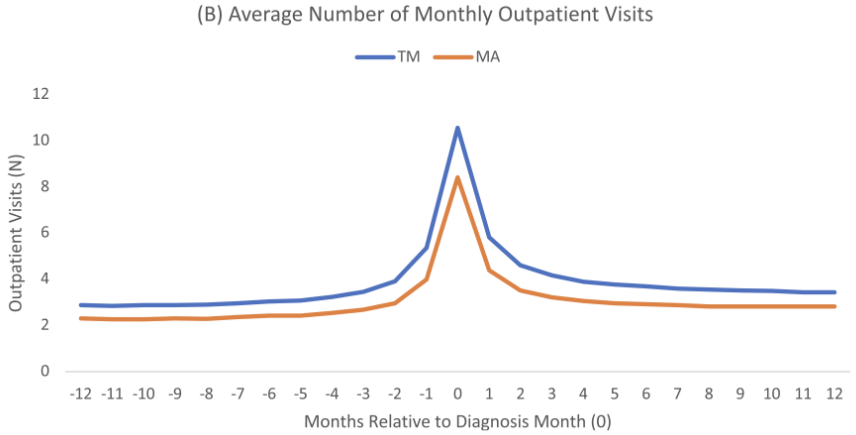


FIGURE 1 Trends in health care utilization in the 12 months before and after an ADRD diagnosis for beneficiaries enrolled in traditional Medicare and Medicare Advantage. Hospitalization rates (A) and average outpatient visit counts (B) by month relative to the month of an ADRD diagnosis for beneficiaries continuously enrolled in traditional Medicare (TM) or Medicare Advantage (MA). Based on Medicare claims and encounter data.

HOSPITALIZATIONS

CRISES ARE MOST COMMON AT MODERATE TO SEVERE DEMENTIA STAGES.

OUTPATIENT VISITS

Jacobson, Ferido, Zissimopoulos
JAGS 2023

Dementia increases preventable hospitalizations

	NEW DEMENTIA	NO DEMENTIA	EFFECT
N	494	2525	16%
Age at enrollment	78 (6)	75 (6)	p = 0.0001
Length of F/U (yrs)	9.6	8	No difference
% w/any admit during followup	**86%**	**59%**	++
% preventable hospitalizations	**40%**	**17%**	**Adjusted rate ratio 1.78 (1.38-2.31)**
2/3 of preventable hospitalizations were for CHF, pneumonia, or UTI. Dehydration and duodenal ulcer hospitalizations occurred *only* among people with dementia. Especially high risk for dehydration and UTI in dementia with poorly controlled diabetes.			

Phelan E et al. JAMA 2012; Zaslavsky O et al,J Gerontol Biol Sci Med Sci 2021

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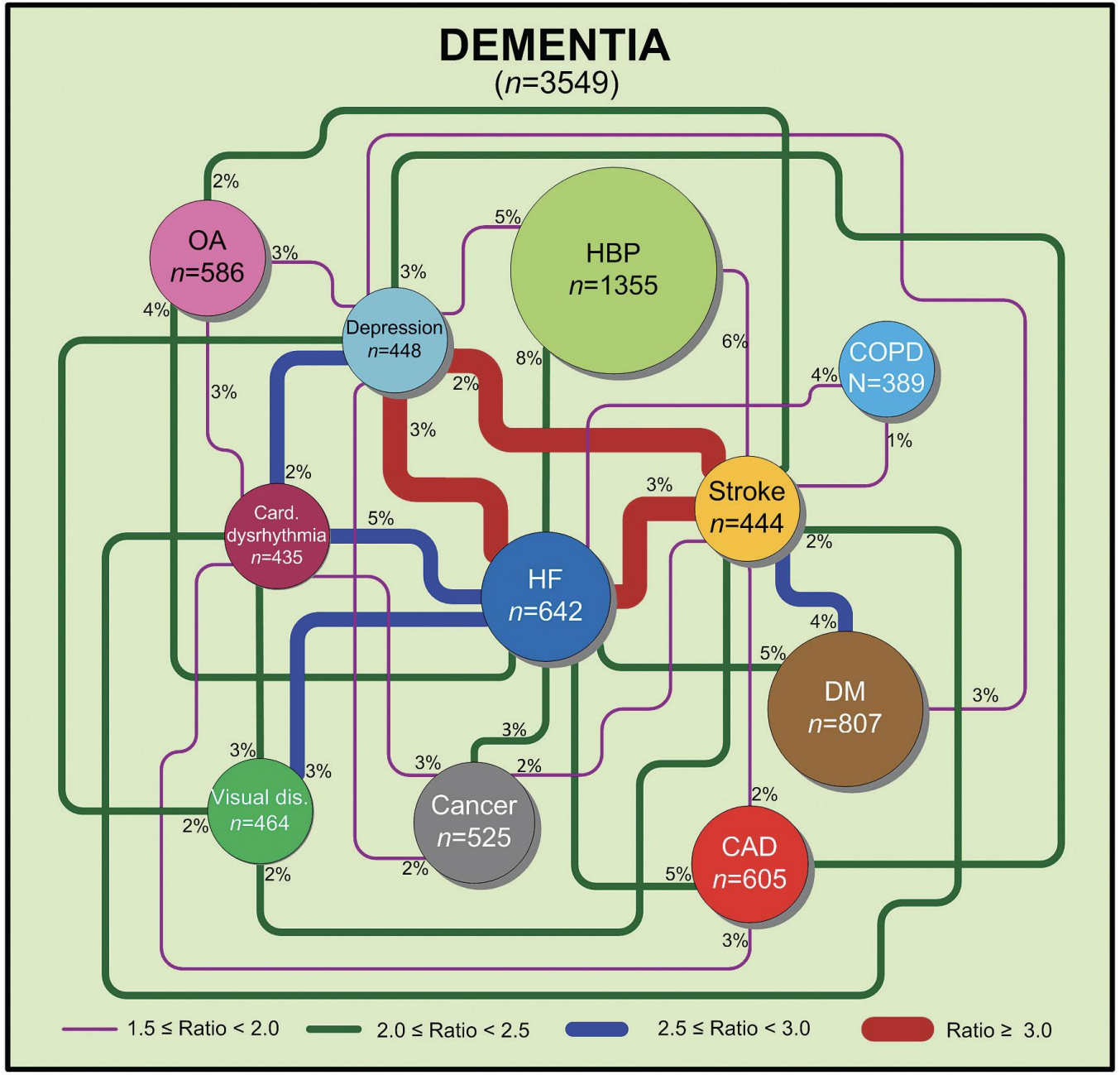

WHY SO LATE? People with dementia often have complex health problems.

- N= 120,480, aged ≥55 and ≥70
- 24 chronic diseases
- 158 general practices in a Netherlands primary care research network, sampled 2002–2011

Sinnige J, Korevaar JC, Westert GP et al. Multimorbidity patterns in a primary care population aged 55 years and over. Fam Pract. 2015;32(5):505-513.

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Why detecting early matters

- Opens the door to the right care, if everyone's prepared and has access to what they need.
- The right care can reduce risk of crisis.
- Most people agree: detecting cognitive impairment at milder stages allows time to adjust and prepare for the future.
  - People with mild cognitive impairment or mild dementia can often help plan their own care.
  - But ~50% are diagnosed at moderate or severe stages when most crises occur.

*Bosisio F, Sterie AC, Rubli Truchard E, Jox RJ. Implementing advance care planning in early dementia care: results and insights from a pilot interventional trial. BMC Geriatr. 2021 Oct 19;21(1):573. doi: 10.1186/s12877-021-02529-8.
*Regier D, Taylor JO, Ho A, Borson S, Turner AM. Care preferences for persons with cognitive impairment: a discrete choice experiment. Alz Dem (in review).

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Why isn't early detection routine?

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Fear

of offending, harming our relationship, feeling stupid

Misunderstanding

the 'why', the 'how', the 'what', and the 'who' can/should do it, what's next

Lack of preparation

somebody else knows more than I do

No one's looking

no required quality measures for dementia detection or care

Feeling powerless

not realizing how much it helps to talk about it – even with no cure!

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Moving toward earlier detection

Start with the people living the problem in silence.

- *Affected people often know something's wrong*
- *Families misinterpret symptoms they see*
- *Care partners lack support*
- *Avoidable crises occur*

Without detection, people...

- worry, cover up, suffer in silence
- get frustrated, relationships suffer
- and endure isolation
- *Anyone* can detect, but health care professionals diagnose

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Why diagnosing earlier matters more now

- We have better understanding and we can do more.
- Getting a diagnosis opens the door to better care for all.
  - Initiate a journey toward agency: taking an active approach to understand, support, and plan.
  - Organize care partnership networks to sustain health and wellbeing for everyone.
  - Consider options – new and older medical treatments; evidence-based psychosocial care; preventive interventions.

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Changes in how we think about dementia and its causes

The Clinical Syndrome

Everything we've been talking about so far today, plus patterns of progression and special features of individual dementia types.

We're getting better at defining the earliest stages of decline (technology)

The Underlying Biology

We can now identify Alzheimer disease biology, even in earliest stages and sometimes before any symptoms occur (technology)

- Imaging
- Blood biomarkers

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Our Center's approach to advancing early detection of dementia

- We help to tailor messaging to the purpose and setting.
- We aim to build strategies together that can be adapted by each partner for their community and their roles.
- We work to amplify and disseminate others' efforts.
  - Partner spotlights, webinars, newsletters, + partners' preferred channels of communication
- We may suggest new roles – e.g. training medical assistants or community health workers to screen for dementia and refer; train RNs in dementia care; bring a Brain Health Navigator into primary care.

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Detection Strategies

Screening individuals

- **When**: concerns about mental function, behavior, communication, activity, unexpected accidents and other indicators are present
- **What**: be alert to changes in behavior or activity that suggest a problem
- Tests of **clinical state** – two ways to screen
  - Cognitive performance testing
  - Questions about functional abilities
- Tests of **biological risk** – future? Blood biomarkers (e.g. for specific brain pathological processes) and genetic risk tests (e.g. apoE4) – *these are not indicators of cognition or clinical state!*

Screening a population

- **When**: we want to find *groups at risk* who may benefit from further evaluation or specialized services or care approaches
- **What**: often use some form of data mining to identify high-risk subgroups
- **Population 'red flags' for higher risk**
  - High/repeated acute health care use – emergency, hospital, urgent care
  - Key social drivers of health, especially low education and low income groups
  - Known medical risk groups (e.g. smokers, people with heart disease, diabetes, hypertension, multiple chronic conditions...)

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Working with individuals: Detection starts with conversation

- Focus on the person and lead with listening
  - "What is most important to you right now?"
  - "What have you done in your life that you are most proud of?"
  - "Are you concerned that things you do are getting harder to do?"
  - "Do you ever worry about your memory?"
- Include care partners as early as you can
  - "I am glad you're here. How are you two related?"
  - "Would it be OK if I asked your [care partner] about how she thinks you are doing?"
  - "Over the course of a day/week do you do things to help [care recipient]? Tell me more."

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Conversation is the first step in care.

- Many (?most) people with dementia have no real “care plan”, and those who do may not know it.
- Care plans start with key evaluations after problem detection, getting a diagnosis, assessing needs, and planning how to meet them now and later.
- Develop a care plan together.
  - “Let’s talk about where you live and what you can do to stay healthy.”
  - “Let’s talk about doing more things you enjoy with friends or family.”
  - “Are there things you’d like or need help with?”
  - “Let’s talk about what’s most important to you to stay healthy - this will also be good for your brain.”
  - “We can do a lot to help you feel better and able to do more of what matters to you.”

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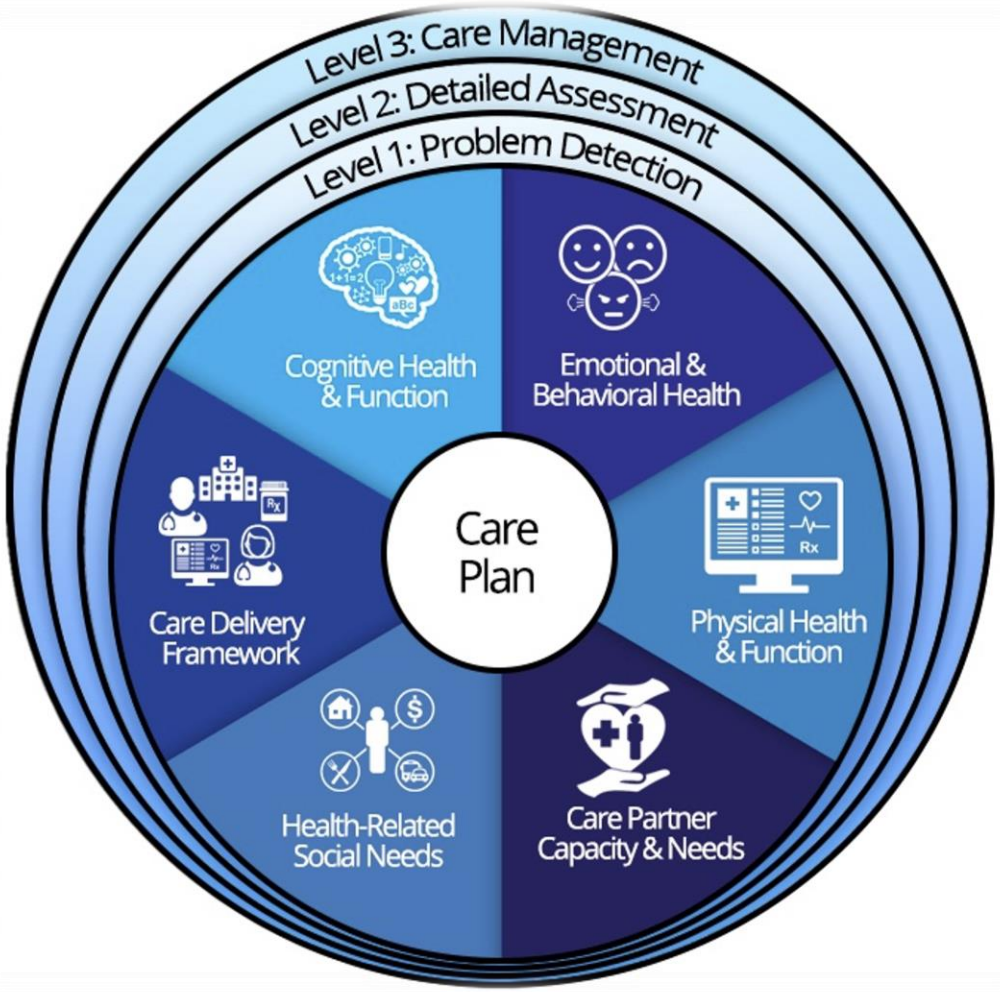
A framework for comprehensive care of people with dementia and their care partners



Six Domains of Health ©S. Borson

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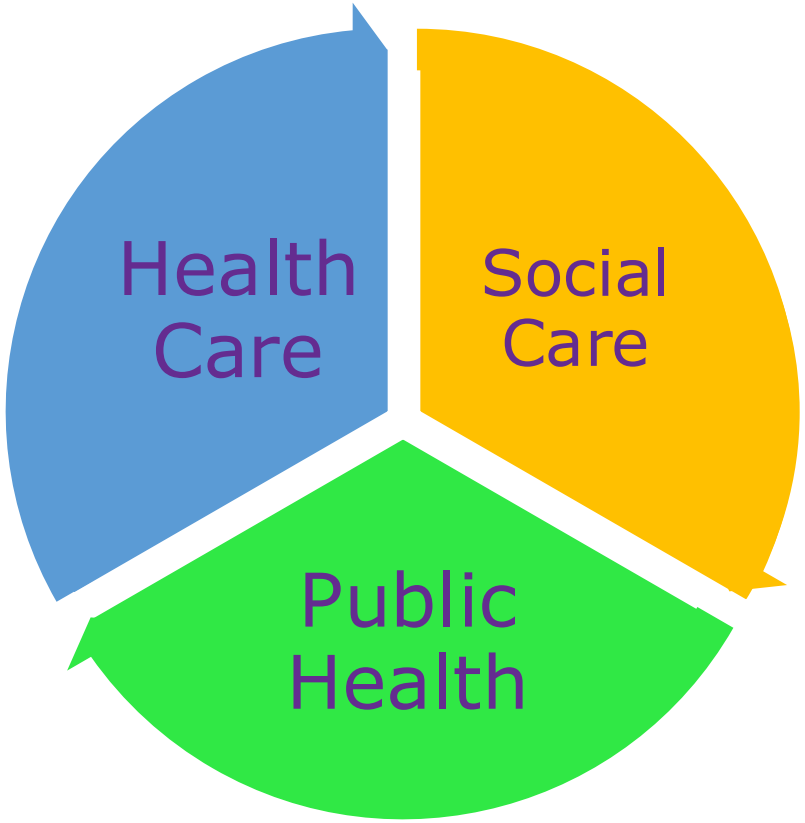
Working with populations for better health: Detection starts with organizations



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Medicare's Annual Wellness Visit (AWV)

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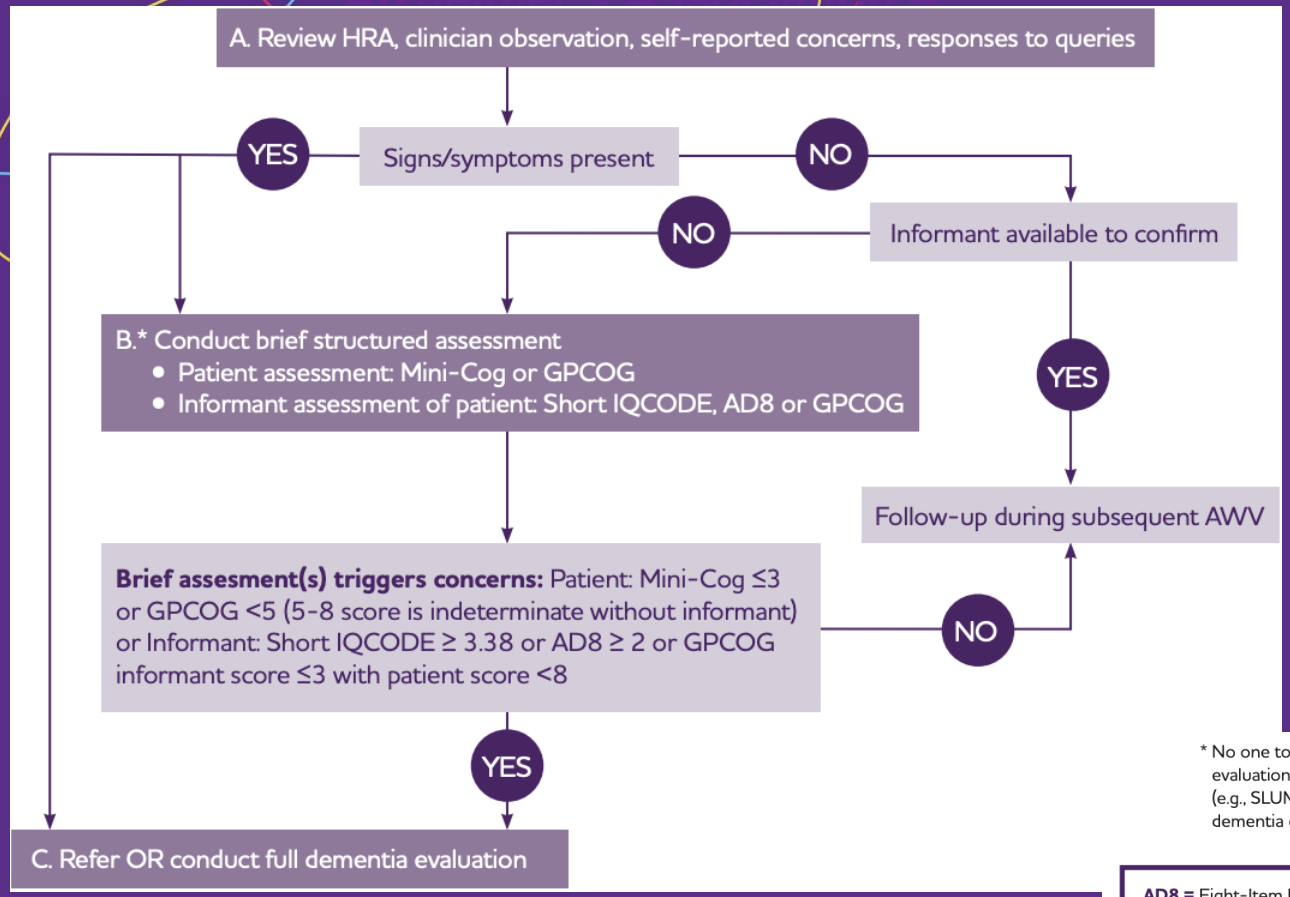

- Requires a focused health risk assessment, detection of any cognitive impairment, and a prevention-oriented care plan.
- Voluntary and free to Medicare beneficiaries.
- Some health systems achieve 80⁺% uptake; national average <50%.

* No one tool is recognized as the best brief assessment to determine if a full dementia evaluation is needed. Some providers repeat patient assessment with an alternate tool (e.g., SLUMS, or MoCA) to confirm initial findings before referral or initiation of full dementia evaluation.

AD8 = Eight-Item Informant Interview to Differentiate Aging and Dementia; **AWV =** Annual Wellness Visit; **GPCOG =** General Practitioner Assessment of Cognition; **HRA =** Health Risk Assessment; **MoCA =** Montreal Cognitive Assessment; **SLUMS =** St. Louis University Mental Status Exam; **Short IQCODE =** Short Informant Questionnaire on Cognitive Decline in the Elderly

- https://www.cms.gov/medicare/payment/fee-schedules/physician/cognitive-assessment
- https://www.cms.gov/priorities/innovation/innovation-models/guide
- Cordell CB, Borson S, Boustani M, Chodosh J, Reuben D, Verghese J, et al. Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. Alzheimers Dement. 2013;9(2):141-150. Available at https://alz-journals.onlinelibrary.wiley.com/journal/15525279

Early Innovator Spotlight: Wisconsin's Early Detection Engine

Dementia Care Navigation as Part of Public Health

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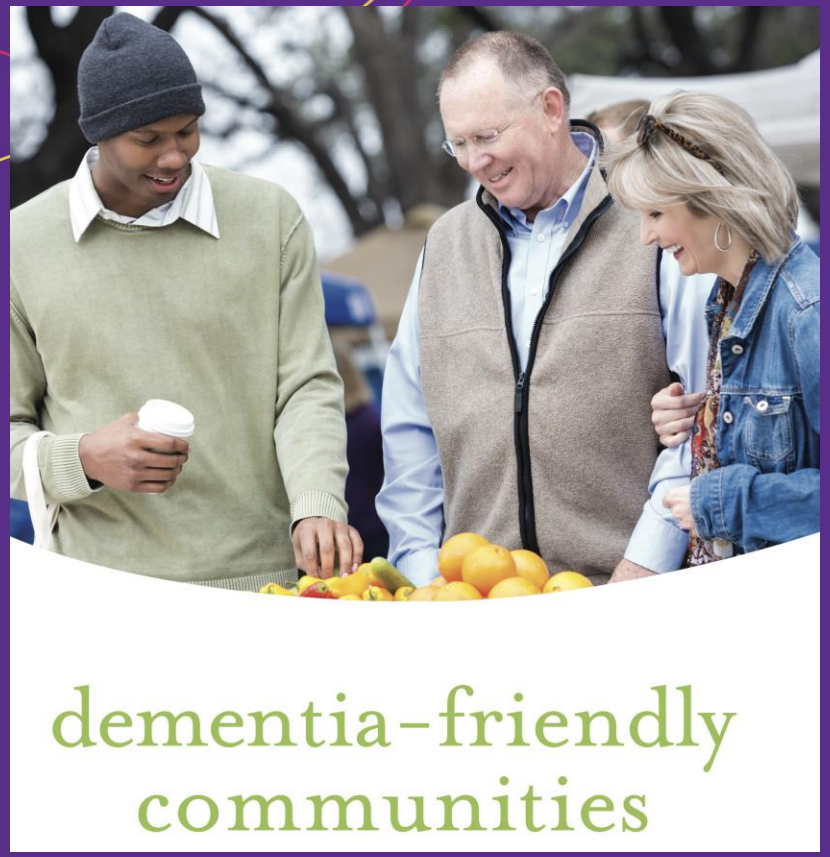
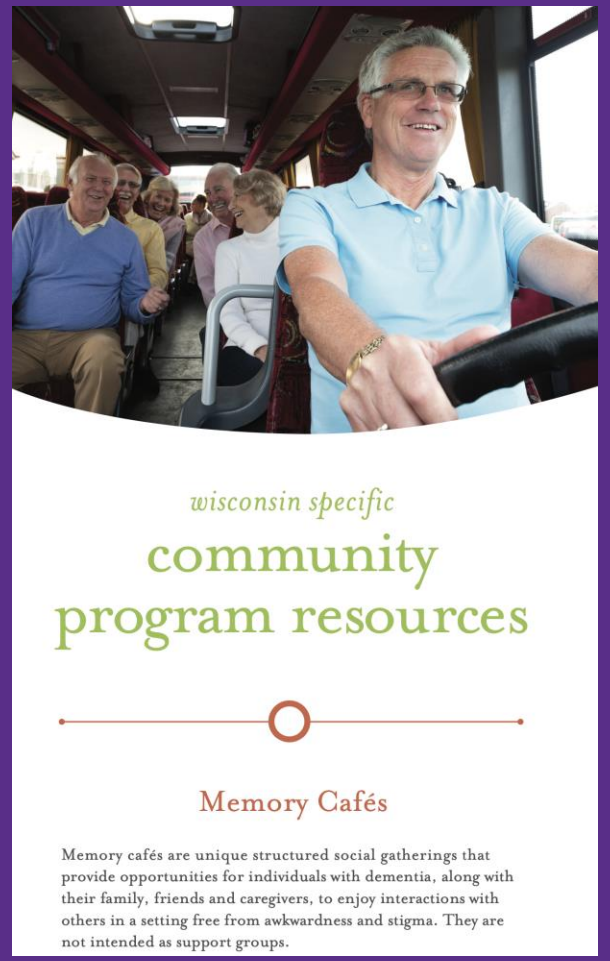
Kristen Felten
Aging and Disability Resource Centers (ADRCs) county-level agencies – free services to public

- Created dementia care specialist program





2023

- 70 Dementia Care Specialists working in Aging and Disabilities Resource Centers, covering all 72 counties and 5 tribes.
- 2021: Dementia Care Specialist program became a state budget line item

ROCK COUNTY
WISCONSIN

WISCONSIN DEPARTMENT of HEALTH SERVICES

Increasing Dementia Detection in Tribal Communities: The Indian Health Service Community Health Representative Mini-Cog Screening Pilot (now in 3rd round)

- Indigenous Americans are disproportionately affected by dementia
- Detection and diagnosis rates historically low
- Goal: improve detection by training community health workers (community health representatives) to screen older adults with a brief validated tool
- Evaluate acceptability (good), adoption (substantial), and referral for next steps in the evaluation and care pathway (improving)

https://www.ihs.gov/alzheimers/pilotsandinitiatives/minicogscreeningpilots/chrscreeningpilot/

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Where are we going with disease-specific blood-based biomarkers and new treatments for degenerative brain diseases?

- Blood-based and neuroimaging biomarkers specific for Alzheimer disease can identify AD pathology in the brain in primary and specialty care settings.
- Some BBMs for AD are now approved by FDA and may be covered by Medicare.
- Biomarkers (blood and imaging) for some other types of dementia are in active development.

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"Novel treatments" now refer mainly to antibodies that remove amyloid from the brain in people with AD, and slow cognitive decline in early stage disease.

- Still some disagreement about amount of clinical benefit.
- A small percentage of patients are eligible for treatment.
  - Early stage only: MCI due to AD and early AD dementia, some medications and conditions excluded.
  - Pre-treatment genetic side effect risk assessment necessary (apoE4).
- Health system adaptation is necessary for implementation. Still mainly available to more advantaged groups.
- Many other types of biomedical treatments are in clinical trials.
  - Some likely to be helpful, applicable to more stages of cognitive decline and other causes of dementia, less restrictive, and easier to use for patients, families, clinicians, and health systems.

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Non-pharmacological interventions: The foundation of lifetime care after diagnosis

- "Whole person, whole family" need-based care is the foundation and quality of life and 'no-crisis" is the goal
- "No-crisis care" integrates contributions of different sectors – health care, community care, and public health
- Can be provided in many different settings
- Key impediments are cultural, financial, disconnected service sectors

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Just a few examples of evidence-based, non-pharmacological interventions

- REACH – caregiver program with training adapted for health care, community organizations, and health department use; targets burden, depression, behavior management skills.
- Care Ecosystem –caregiver focused telephonic care navigation by lay team members. Can escalate to team nurse or social worker if needed.
- D-Care – collaborative care model led by nurse practitioners (health care) or social work staff (community organization). Both are preferred by caregivers over usual care.
- HABC – care navigator attached to clinical memory team.

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The GUIDE Model: Bringing Health and Social Care Together through Dementia Care Navigation

CMMI's Alternative Payment Model for Dementia 2023 – enrollment started 2024

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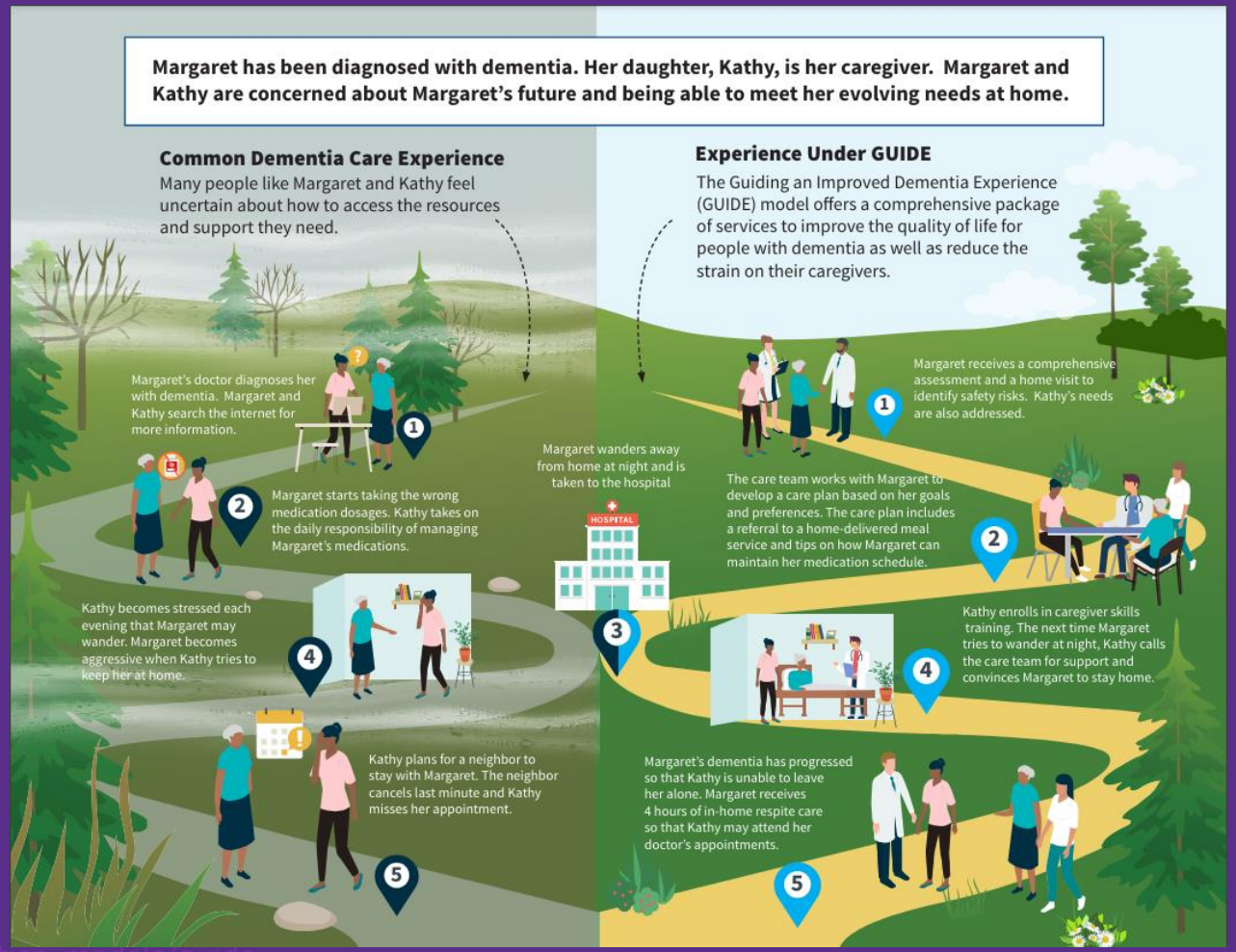
- 330 sites currently operating
- 8 year pilot
- Based on research evidence
- Goals: improve QoL for patient and caregiver, reduce acute care use, delay nursing home placement, improve medication management, and reduce costs of care.



https://www.cms.gov/priorities/innovation/innovation-models/guide

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Prototyping a Dementia Detection and Care Program in a Health System

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Hospital Inpatient Services

Age-Friendly Hospital Measure: 4M's $

- What Matters
- Mentation
- Mobility
- Medication

Clinic Services

Primary Care

✓Concern for Possible Cognitive Impairment

Brain Health Navigator

Protocol Driven:
- ✓Assessment
- ✓Referral(s)

Digital Support

Primary Care

Specialty Care

Diagnosis

GUIDE

✓Post-Diagnosis Dementia Specific Services

$ CMS requirement (penalty)

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Opportunities for collaboration and support

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Toolkit for Health Systems

bolddementiadetection.org/resources/#toolkit

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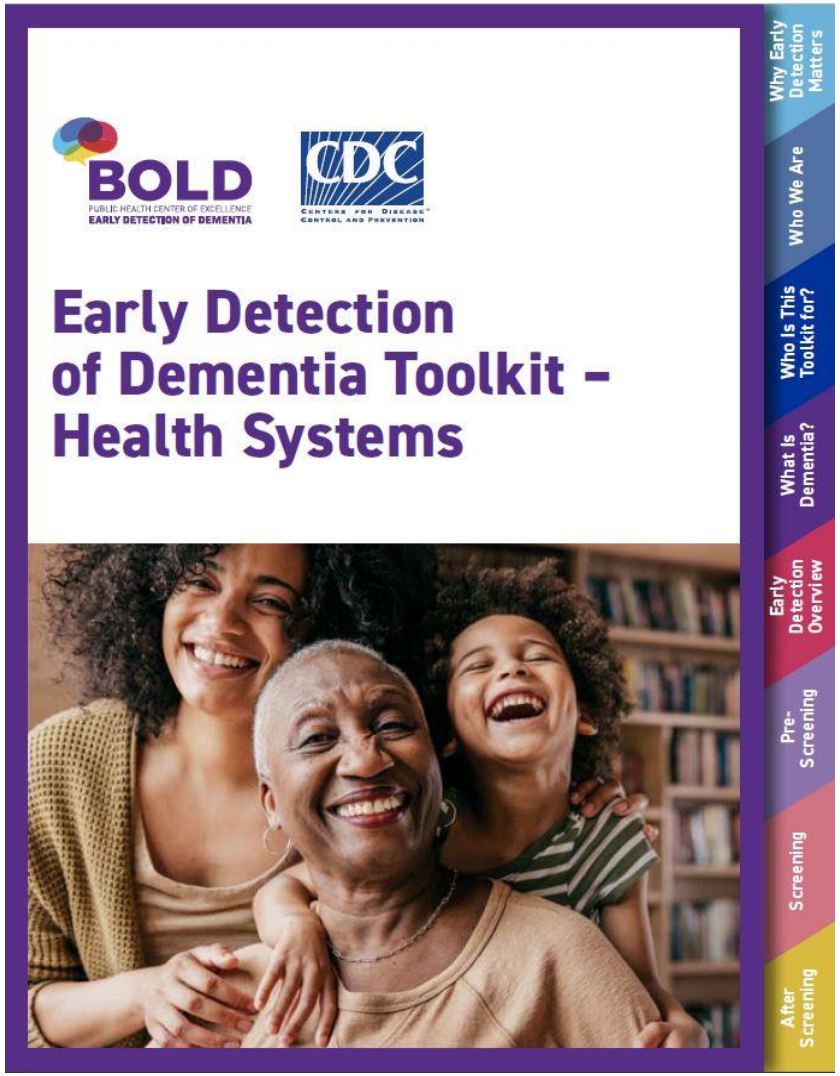

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Coming This Year!!

bolddementiadetection.org/resources/#toolkit

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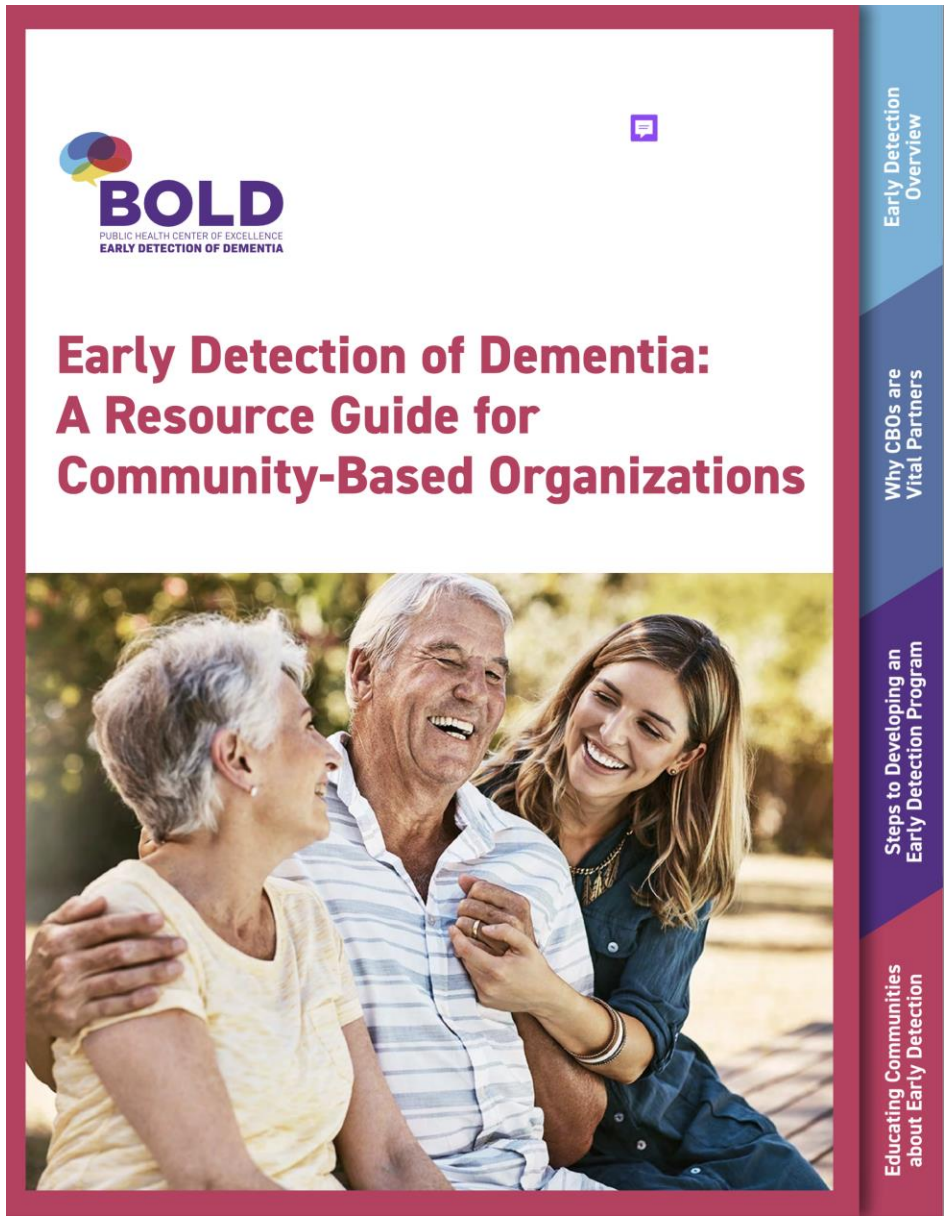

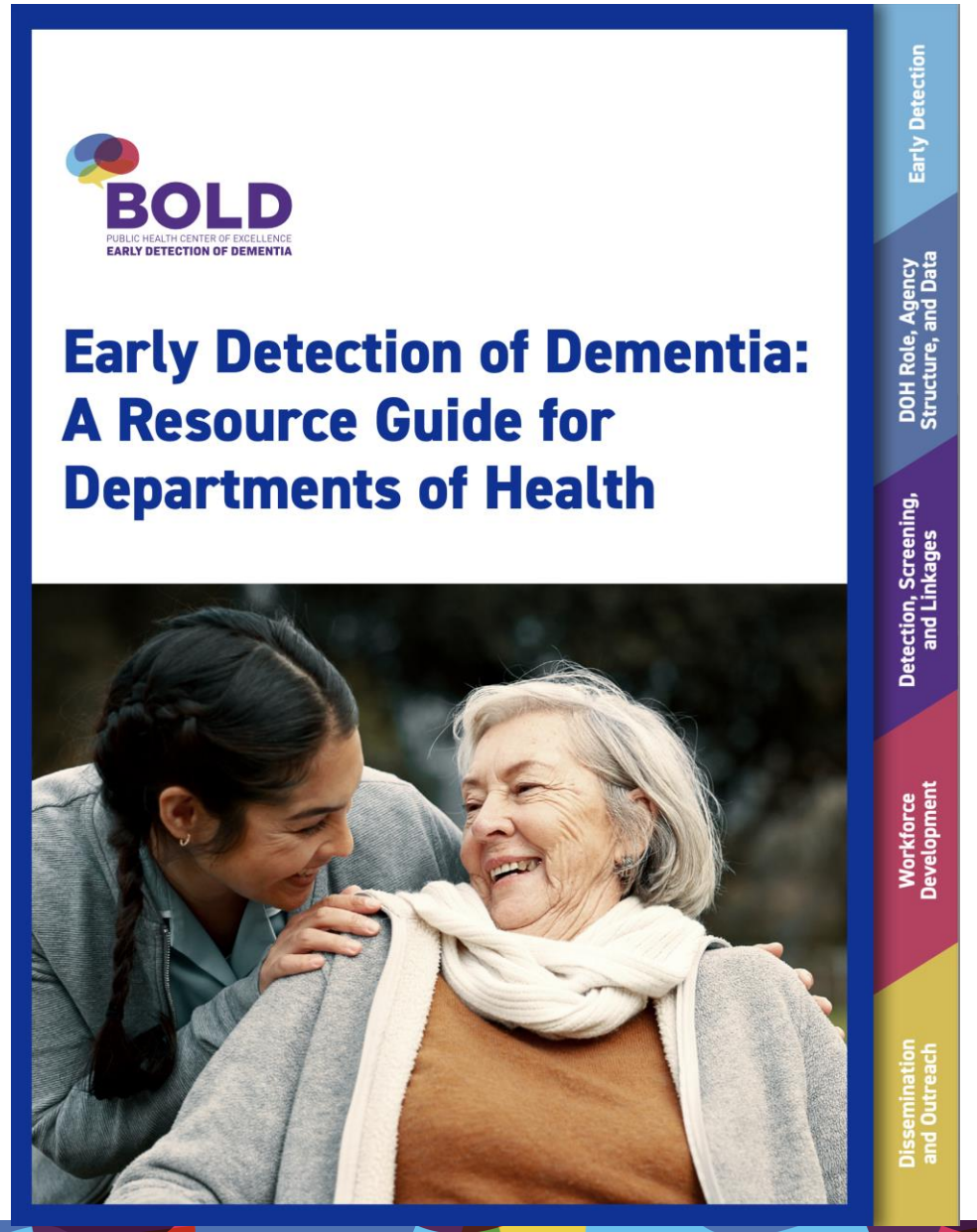

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Implementation and Sustainment Decision Tree

https://bolddementiadetection.org/resources/implementation-and-sustainment-decision-tree/

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Implementation and Sustainment Decision Tree

Abbreviated tool below

Explore

- Have you chosen an early detection approach (program, process, policy, practice, guideline) to implement and sustain in your setting?

Prepare

- Do you have the capacity, champions, buy-in, resources, and leadership support to successfully implement your selected early detection approach?

Implement

- Initial/Early Implementation: Are you confident in your approach to evaluating the success of your early detection effort?
- Mid- to Late-Term Implementation: Has your early detection approach been fully implemented? Can it be sustained to meet dynamic needs + priorities over time?

Sustain

- Do you have a plan for longer-term implementation and sustainment of your early detection approach? How will you identify potential gaps in what has been implemented?
- Do you have a process in place to monitor ongoing sustainment and continuous quality improvement?

Acknowledgement: Phases for this decision tree follow those of the EPIS Implementation Framework
https://episframework.com/

https://bolddementiadetection.org/resources/implementation-and-sustainment-decision-tree/

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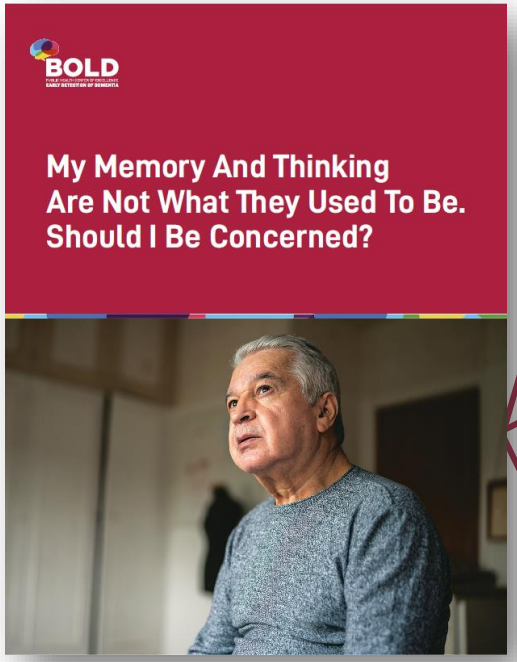
Patient-Provider Worksheet

Printable worksheet to help individuals plan to talk with a health care professional about memory concerns.



What is dementia, MCI, and Alzheimer's?

Should I tell my doctor about my memory concerns?

Are you ready to talk to your doctor?

1. Are you concerned about your memory or thinking?
   ____ yes ____ no
2. Describe your concerns about your memory and thinking. For example, are there specific situations or things that worry you?
   _____
   _____
   _____
3. Has anyone else noticed changes in your memory or thinking (a family member, partner, friend or acquaintance, another health care professional, or other)?
   ____ yes ____ no
   If yes, describe what they noticed:
   _____
   _____
4. Is this your first time discussing these concerns and symptoms with a health care professional?
   ____ yes ____ no
   If no, what did you discuss and what was the result?
   _____
   _____
5. Think about your memory and thinking a year ago. Have your symptoms gotten worse, better, or stayed the same?
   ____ worse ____ better ____ stayed the same

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Post Diagnosis Worksheet

This resource explains what individuals can expect and what steps to take next after receiving a dementia diagnosis.

Learn what to expect

Ask questions that matter to you

Sample questions to ask your doctor

Sample question topics cover:

- Understanding your dementia diagnosis
- Who is on your care team & how to communicate with them
- Setting up your care plan
- Understanding your legal & financial options
- What programs and resources can help you
- Understanding your physical health, mental health, and medications

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Many public health organizations (local, county, and state) have embraced and are engaged in achieving better dementia detection and care

Exemplars

California
Vermont
Georgia
Maine

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California

DHCS

- Annual Cognitive Health Screen (CHS) for all Medicaid recipients aged 65+
- Developed by Dementia Care Aware – free, comprehensive web-based training and tools for clinicians and teams
  - Basic education about dementia
  - How to do and interpret the CHS (cognition and function), include caregivers on the team, develop a care plan, and manage common problems
- Special clinician incentive (Medi-Cal billing code)
- Now being evaluated for uptake and impact on dementia detection

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Vermont

Supporting Primary Care

Project ECHO:

- University of Vermont (UVM) Dementia Diagnosis and Care for the Primary Care Team

VT Health Learn

- Partnership between OneCare VT, VT DOH, Department of VT Health Access, and VT Blueprint for Health
- Free, statewide, e-learning platform
  - Dementia module: *Dementia Diagnosis, Treatment and Management for Primary Care Teams*

Dementia Corner Consults

- Gives providers a regular opportunity to engage remotely with one of the Medical Directors of the UVMHN Memory Program.
- One-on-one discussion slots for complex dementia issues

https://dail.vermont.gov/sites/dail/files/documents/BOLD_Alzheimers_and_Healthy_Aging_Program_4-8-21.pdf
https://bolddementiadetection.org/wp-content/uploads/2022/06/Vermont-BOLD-Partner-Spotlight.pdf

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Georgia

Extending Their Reach Through Telemedicine

Telehealth Pilot Project

- GA DPH initiated telehealth pilot project in 2003; formal network buildout in 2012; Statewide connectivity in 2016
- GDPH partnered with local health departments to pilot a project linking patients in rural counties to providers and specialists
- Specialists conduct telemedicine visits via tablets
- These visits are focused on arriving at a diagnosis of cognitive condition

Project Extension for Community Healthcare Outcomes

- Telementoring program to strengthen provider workforce; Initiated in 2019

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Maine

FQHC-BOLD partnership

- Maine BOLD, HealthReach FQHC Network, and NYU BOLD Center co-developed and provided trainings
  - Topics include:
    - How to have these conversations
    - How to initiate a care plan
      - Three patient cases (non-pharmacological management)
    - How to make a diagnosis

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Partner Activities: Key Strategies

Public – Academic Partnerships leverage mutually needed resources

- Telehealth – addressing issues reach and scalability (equity)
- Project ECHO – broad educational reach (equity)
- Annual wellness visits
- Webinars
- Website resources

Linking public health – community resources

- Outreach
- Dementia-informed community services

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Looking ahead:
Emerging issues and ADRD priorities

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Building a dementia-capable workforce

Cross-sector collaboration

- Dementia can be detected wherever people living with dementia are found – at home, in the supermarket, at the bank, on the bus, at the park, at the food bank, in the senior center, at your local pharmacy.
- Strengthening cross-sector referrals, hand-offs, or partnerships
- Identifying and incorporating cross-sector training components

Engaging Community Health Workers

- CHWs are well-positioned to bridge public health, clinical care, and community-based services, especially in communities with elevated dementia risk
- Our Three Centers call for dementia-specific training aligned with CHW Core Professional Roles and Competencies, as well as national frameworks for dementia such as the HBI Road Map and the CMS GUIDE Model

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Technical Assistance – How Can You Engage with BOLD?

Our Center provides various types of technical assistance (TA) depending on your organization's needs.

Information & Education

Decision-making

Capacity Building

Networking & Partnerships

Strategic Planning

Starting where you are

- What are your active challenges?

BOLD can work with you to …

- Guide you in channeling current efforts toward early detection
- Clarify your approach and thinking

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Thank you!

Let's Stay in Touch!

Sign up for our Center's quarterly newsletter

For all your technical assistance (TA) needs, please complete our Center's TA form

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