

# Dementia Ideal Care Map: Ecosystem View of Best Practices and Care Pathways *Enhanced by Technology and Community*

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## Wen Dombrowski, MD, MBA Perspectives



- Dementia Care Worker
- Geriatrics Physician
- Executive in Health Systems (CMIO / CIO)
  - Care Model Designer
  - Clinical Informaticist
  - Process Engineer
- Tech / Innovation Consultant to Payers, Providers, Government, Investors, Startups, Medical Device, Pharma, Retail, Community Orgs

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## Background & Aims

- Nonprofits, industry, and academics globally have identified best practices to support PLWD
- However, best practices tend to:
  - Only focus on **1 phase** of patient journey
  - Only focus on **1 relevant group**
  - Reside in **disparate repositories**
- The **Dementia Ideal Care Map** aims to bridge this gap by including:
  - **Ecosystem view** of ideal care
  - Best practices **beyond physicians'** medical decisions
  - **Technologies** that enhance care
  - **Proposed new** care pathways, processes, services, and quality measures
- **Actionable tool** for policymakers, researchers, technology developers, health system leaders, clinicians, social services workers, patient advocates, PLWD, families, and communities
- Ultimately to improve quality of life (QoL)

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## Methods

*"Ideal Care"* in this project means:

What would be **optimal** dementia care in the near future, **if not limited** by current constraints & feasibility?

What would be the **ideal PLWD experience** from before diagnosis through ongoing care?

1. **Searched** for best practices
2. **Excerpted & synthesized** from >100 global sources
3. **Visually summarized** in diagram (adapted from **Capabilities Architecture**)
4. **Visually analyzed** draft diagram **to identify gaps/barriers**
5. **Brainstormed** other processes, services, & quality measures to overcome gaps
6. **Added technologies** that enhance care (most already available)
7. **Sought feedback**
8. **Revised diagram** based on feedback

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# Results

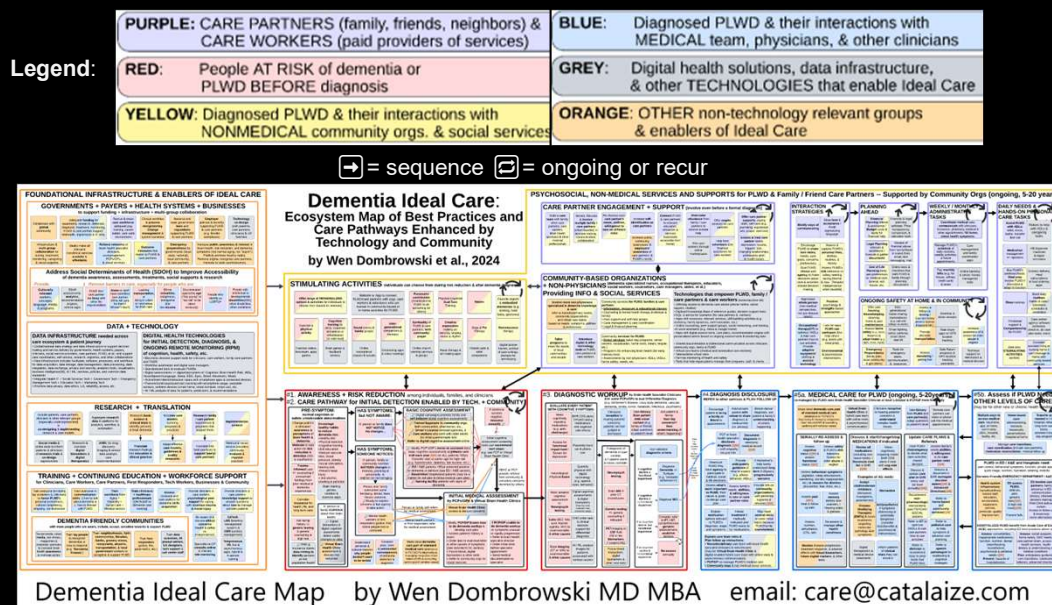
The **Dementia Ideal Care Map** summarizes in 1 comprehensive diagram:

- **Dementia ecosystem** of relevant groups
- **>200 best practices**
- **~100 technology enablers**
- **Other infrastructure**
- **Enhanced care pathways**

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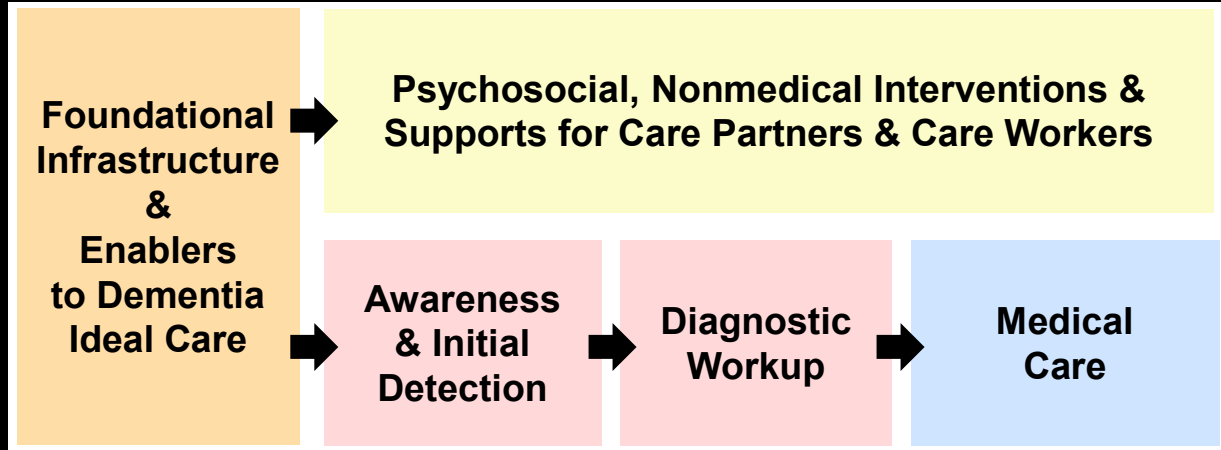
## Ideal Care Map: At-A-Glance



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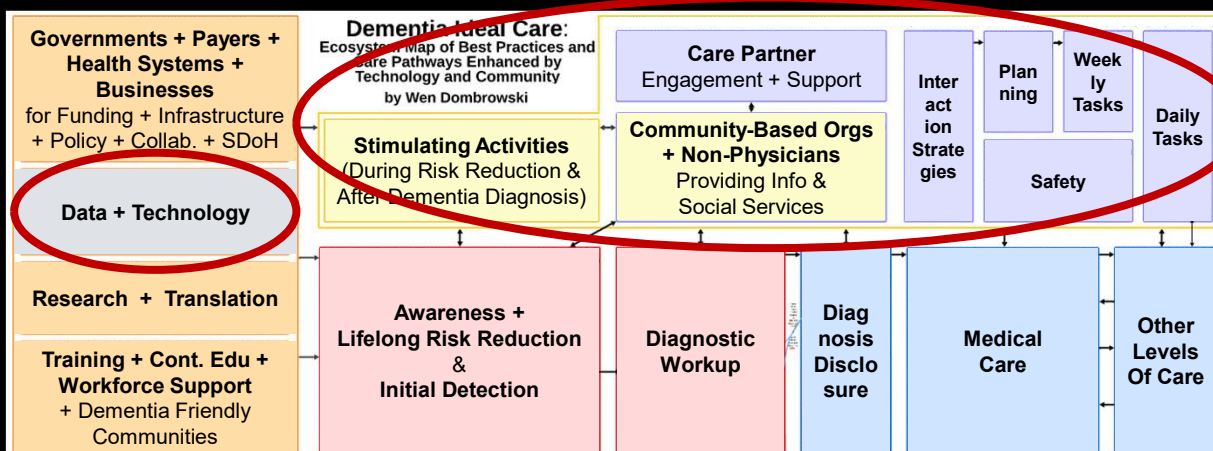
# Ideal Care Map > Typical Care Pathways



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# Ideal Care Map: Overview of Sections



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# Tech Infrastructure

## **DATA INFRASTRUCTURE needed across care ecosystem & patient journey**

- Global/national data strategy and data infrastructure to support decision making and service delivery by governments, health systems, payers, clinicians, social service providers, care partners, PLWD, et al.; and support care coordination, self-service, research, registries, and other collaborations
- Data Infrastructure includes hardware, software, processes, and workforce for data acquisition, data storage, data management, data processing, data integration, data exchange, privacy and security; analytics tools, visualization, business intelligence(BI), AI / ML; services, policies, and common data standards
- Integrate Health IT + Social Services Tech + Government Tech + Emergency Management Tech + Education Tech + Marketing Tech
- Prioritize data privacy, data ethics, UX, reliability, access, etc.

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# Tech Solutions

## **DIGITAL HEALTH TECHNOLOGIES for INITIAL DETECTION, DIAGNOSIS, & ONGOING REMOTE MONITORING (RPM) of cognition, health, safety, etc.**

- Electronic decision support tools for clinicians, care workers, family care partners and PLWD
- Workflow automation and digital case managers
- Standardized tools to evaluate PLWDs
- Digital assessments +/- digital biomarkers of: Cognition, Brain Health Risk, IADL, Voice/Speech/Language, Sleep, EEG, Eyes, Smell, Movement, Mood;
- Active/intermittent/interactive inputs with smartphone apps & connected devices
- Passive/continuous/automatic tracking with smartphone usage, wearable sensors, ambient devices (smart home, smart furniture, smart car), etc.
- AI / ML analysis of data for patterns, predictions, & recommendations

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# Activities During Risk Reduction & After Diagnosis

**STIMULATING ACTIVITIES** individuals can choose from during risk reduction & after dementia diagnosis

Offer range of <b>PERSONALIZED options &amp; activities</b> for individuals to choose from (based on interests)	Website or App to connect PLWD/care partners with orgs, care workers & volunteers who are trained in community-based or in-home activities for PLWD	<b>Purposeful contribution</b> (meaningful for PLWD to do something for others)	Physical-Cognitive Dual Task Training	Nature	Favorite objects & embodied memories (e.g. knitting, hold baby, gestures)		
<b>Exercise &amp; physical activity</b>	<b>Cognitive training</b> (in MCI). Cognitive stimulation or rehabilitation (in mild-mod)	<b>Social events &amp; hobby groups</b>	<b>Inter-generational companions &amp; mentees</b>	<b>Spirituality</b> of PLWD & care partners; <b>faith community; prayer</b>	<b>Creative expression:</b> making art, dancing, singing, music & rhythm	<b>Dogs &amp; Pet Therapy</b>	<b>Reminiscence therapy</b>
Exercise videos, livestream, apps, games	Brain games & feedback devices	Online recreational classes & socials	Connecting apps & video meetings	Online church worship services & groups	Music therapy & art-making apps	Robotic pets & robot companions	Digital picture frames, archive of past writings, prompts for reminiscing

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# CBOs Providing Info & Social Services

**COMMUNITY-BASED ORGANIZATIONS + NON-PHYSICIANS** (dementia specialized nurses, occupational therapists, educators, social workers, counselors, care managers, aides, et al.)

**Providing INFO & SOCIAL SERVICES**

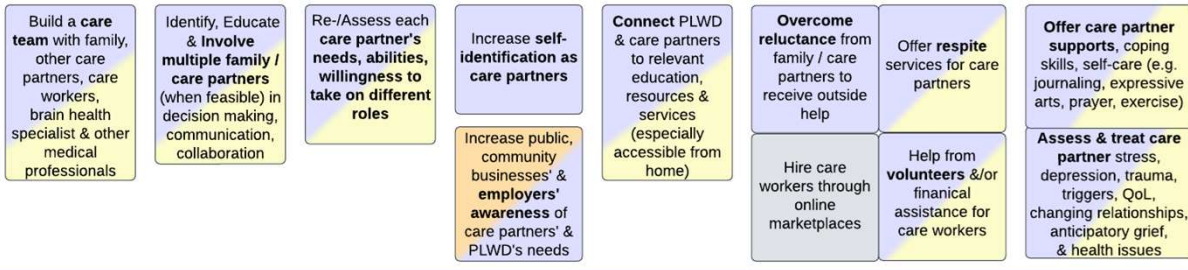
<b>Involvement of non-physicians specialized in dementia knowledge &amp; care:</b> refer to transdisciplinary teams, community organizations, and virtual care teams based on needs, symptoms, abilities & preferences	<b>Community services for PLWD, families &amp; care partners:</b> • <b>Information, resources &amp; educational classes</b> • Counseling & mental health therapy (individual & family) • Peer support and self-help groups • Case management & care coordination • Legal & financial planning	<b>Technologies that empower PLWD, family / care partners &amp; care workers</b> (nonexhaustive list) • 24hr/day access to dementia care advice (phone hotline, online support, chatbot) • Digitized Knowledge Base of reference guides, decision support tools, FAQs, & advice for scenarios (for care partners & workers) • Apps with resources, relevant services, skill-building activities (e.g. resiliency, family dynamics, communication, etc.) • Online counseling, peer support groups, social networking, and training • AI voice assistants (e.g. Alexa & Google Home) • Apps with digital assessments, care plans, recommendation engine with personalized advice based on ongoing assessments & monitoring data  • Shared documentation & bidirectional communication across clinicians, community orgs, family & PLWD • Virtual care teams (medical and nonmedical care workers) • Telemedicine virtual visits • Remote monitoring of health and safety • Tools that help organizations manage their programs, staff, & clients
<b>Tailor programs</b> to meet the needs of local communities and people	<b>Community services for PLWD:</b> • <b>Direct services</b> (adult day programs, senior centers, socialization, home visits, meals, respite, etc.) • Programs for enhancing brain health (for early memory loss) • Assessments by non-physicians: ADLs, IADLs, home safety, needs, etc.	

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# Engaging & Supporting Families, Friends, & Other Care Partners

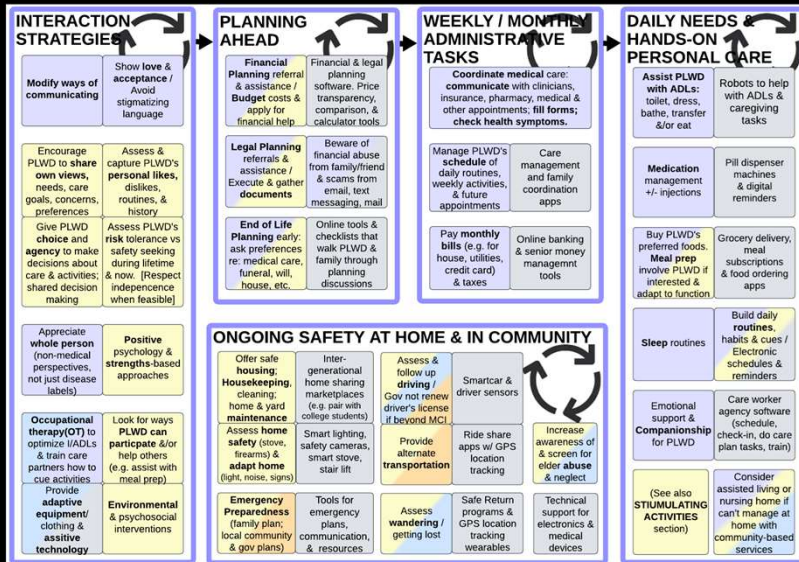
## CARE PARTNER ENGAGEMENT + SUPPORT (involve even before a formal diagnosis)



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# Best Practices for Care Partners & Care Workers



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Potential Process Measures for Ideal Care of People Living With Dementia (PLWD)

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**Medical Care**

- Administer basic cognitive assessment annually to all people over age 65 (or earlier age for individuals in high-risk groups).
- Assess older adults in hospitals using guidelines from Geriatric-Friendly Emergency Department (Geri-ED) and Acute Care of Elders (ACE)
- Perform diagnostic workup (would need to specify which essential components must occur, such as neurologic exam, which blood tests, imaging test)
- Disclose diagnosis to PLWD
- Document dementia diagnosis in medical record/EHR
- Assess family's needs, abilities, and willingness to take on care partner role(s)
- Document care partner(s) and surrogate decision maker
- Provide info about support organizations to PWLD and/or care partner
- Refer to home-based and/or community services
- Assess cognitive status serially
- Assess functional status serially
- Assess pain serially
- Reconcile medications serially
- Discuss and update care plan serially

# Quality Measures

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# PROM

Examples of Dementia-Specific Patient Reported Outcome Measures (PROM) of Quality of Life (QoL)

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- Alzheimer's Disease-Related Quality of Life (ADRQL)
- Bath Assessment of Subjective Quality of Life in Dementia (BASQID)
- Dementia Quality of Life Measure (DEMqoL)
- Dementia Quality of Life (D-QoL)
- Family Quality of Life in Dementia (FQOL-D)
- Quality of Life in Alzheimer's Disease (QoL-AD)
- Quality of Life in Late-Stage Dementia (QUALID)
- QUALIDEM

**Social Services**

- Document PLWD's personal life goals, care goals, routines, likes and dislikes
- Complete dementia care training (% clinicians and care workers)
- Provide nutritious meals (e.g., if government is paying for someone to take care of PLWD)

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## Observations from Visual Analysis

- Informative to see best practices in **1 compact view** –
  - **Ecosystem View** including **all relevant groups** reveals **interdependencies & bottlenecks**
  - **Person-Centered, Life Course View** shows **psychosocial** best practices can begin **before** a diagnosis (e.g. stimulating activities & interactions with patient advocacy associations)
- **Journey is Non-linear**: each step may be **recurring, continuous, or fluctuating** intensity
- **Post-diagnosis survival** can increase to **5~20 years**
  - As more public health innovations + more PLWD diagnosed earlier + new clinical treatments
  - Important to communicate wide range of survival & anticipatory guidance
- Much **workload** for risk reduction, detection, & after-diagnosis care can be shared by **multidisciplinary & virtual care teams** (not expecting PCP/GP or specialists to "do it all")
- **Technologies** can augment human efforts
  - e.g. AI/ML, decision support, personalized recommendation engines, remote monitoring, etc.
  - *Ideally* the tech should **bridge all stages** of life & disease, and **all relevant groups**
  - Therefore, many grey boxes *ideally* as horizontal bars **across entire diagram / journey**

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## Potential Applications & Collaborations

- Welcome **feedback & collaborators** to iterate & build upon [Linktr.ee/caremap](https://linktr.ee/caremap)
- Create online **interactive version** to crowdsource feedback, link to more info, filter views
- **Customize & adapt** the Ideal Care Map to specific **relevant subgroups, geographic regions, dementia subtypes, other conditions** (neuro, diabetes, rare disease, long COVID, aging)
- For **policymakers, health systems, community organizations, businesses, technology developers, educators, media, & other leaders:**
  - Use as high-level **roadmap** of what needs to be done for **capacity building, service planning, interagency & intersectoral collaboration**
  - Tool for **gap analysis, heatmapping, capability maturity planning**
- For **clinicians, care workers, & researchers:**
  - **Familiarize** with the breadth of **interventions beyond own roles** & the **transdisciplinary coordination** needed for Ideal Care
  - **Inform development** of research agendas, clinical protocols, decision support tools, quality measures, digital measures, & patient reported outcomes
- For **PLWD, care partners, & lay people:**
  - Learn **what to consider** at different phases
  - **Co-design** with PLWD & care partners to adapt into **personalized journey tool** for laypeople

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## Thank you! Questions?

**Dementia Ideal Care Map:**  
Ecosystem View of  
Best Practices and Care Pathways  
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