Dementia Care: Getting It Right for Everyone

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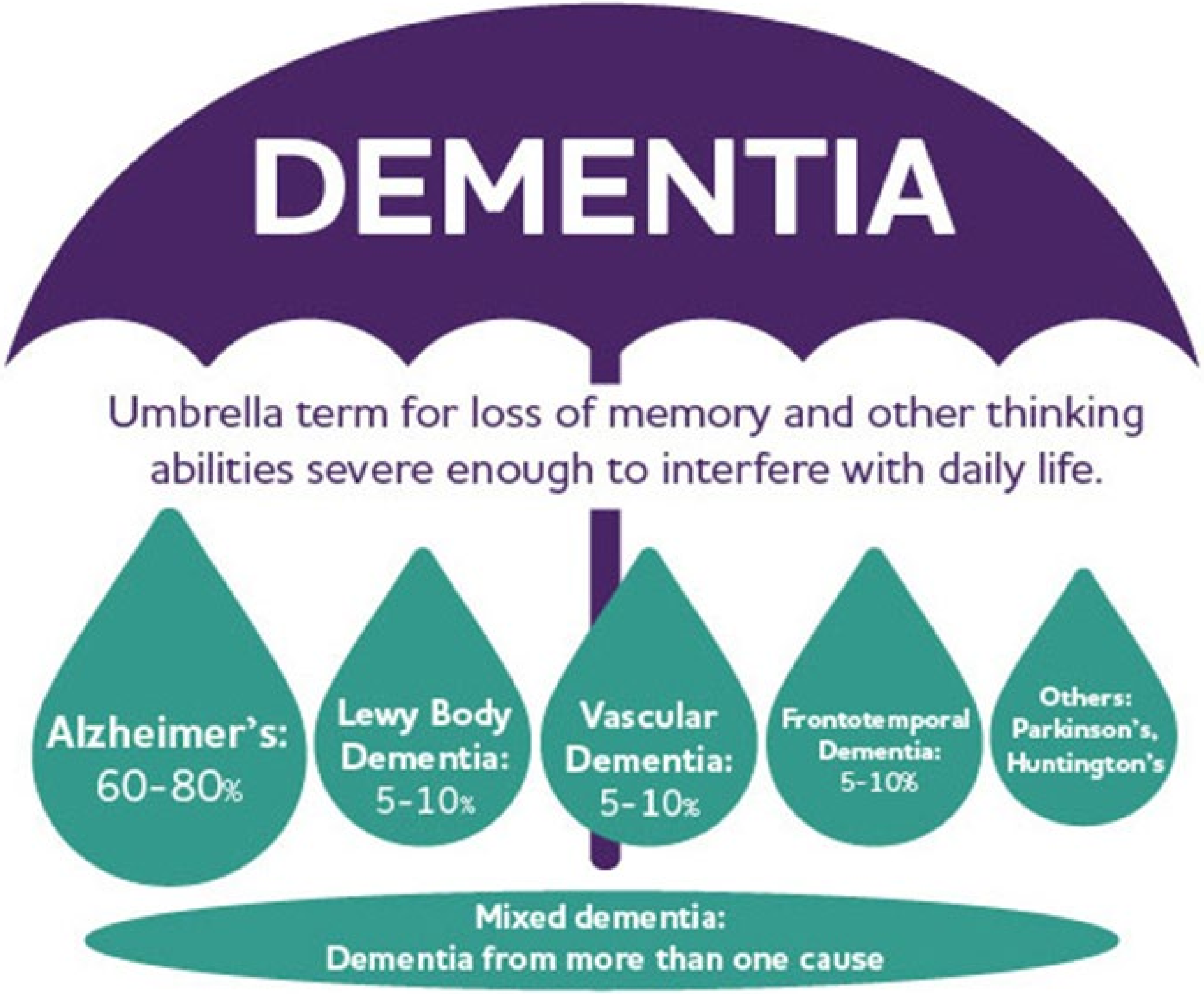
Diseases Causing Dementia



DEMENTIA

Umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

Alzheimer's: 60-80%

Lewy Body Dementia: 5-10%

Vascular Dementia: 5-10%

Frontotemporal Dementia: 5-10%

Others: Parkinson's, Huntington's

Mixed dementia: Dementia from more than one cause

The 21st Century Plague

- Prevalence of Alzheimer’s dementia

Age range	% affected
65–74	5%
75–84	13%
85 and older	33–50%

- 6.5 million Americans affected (2022)
- 7.2 million by 2025
- Higher rates in African Americans (much higher) and Latinos

Alzheimer’s Disease: 2011

- 3 stages
  - Preclinical: normal cognition; defined by changes in biomarkers
  - MCI: impaired cognition, intact function; positive biomarkers; may help determine progression to dementia
  - Dementia: impaired cognition; impaired function; biomarkers may be helpful in excluding AD as cause

Care for PLWD is expensive

- Total payments $321 billion (2022)
    - Paid for by Medicare and Medicaid $206 (64%)
    - Out of pocket costs to families $81 billion (25%)
- Unpaid caregivers provided ~16 billion hours valued at $271.6 billion (2021)
- Lifetime cost of care of PLWD: $371,621 (2021).

…and is of Mediocre Quality

- Overall Dementia Quality of Care (ACOVE-3 and PCPI Quality Indicators)

Community-based physicians	38%
Community-based physicians & NP	60%
UCLA Alzheimer's and Dementia Care	92%

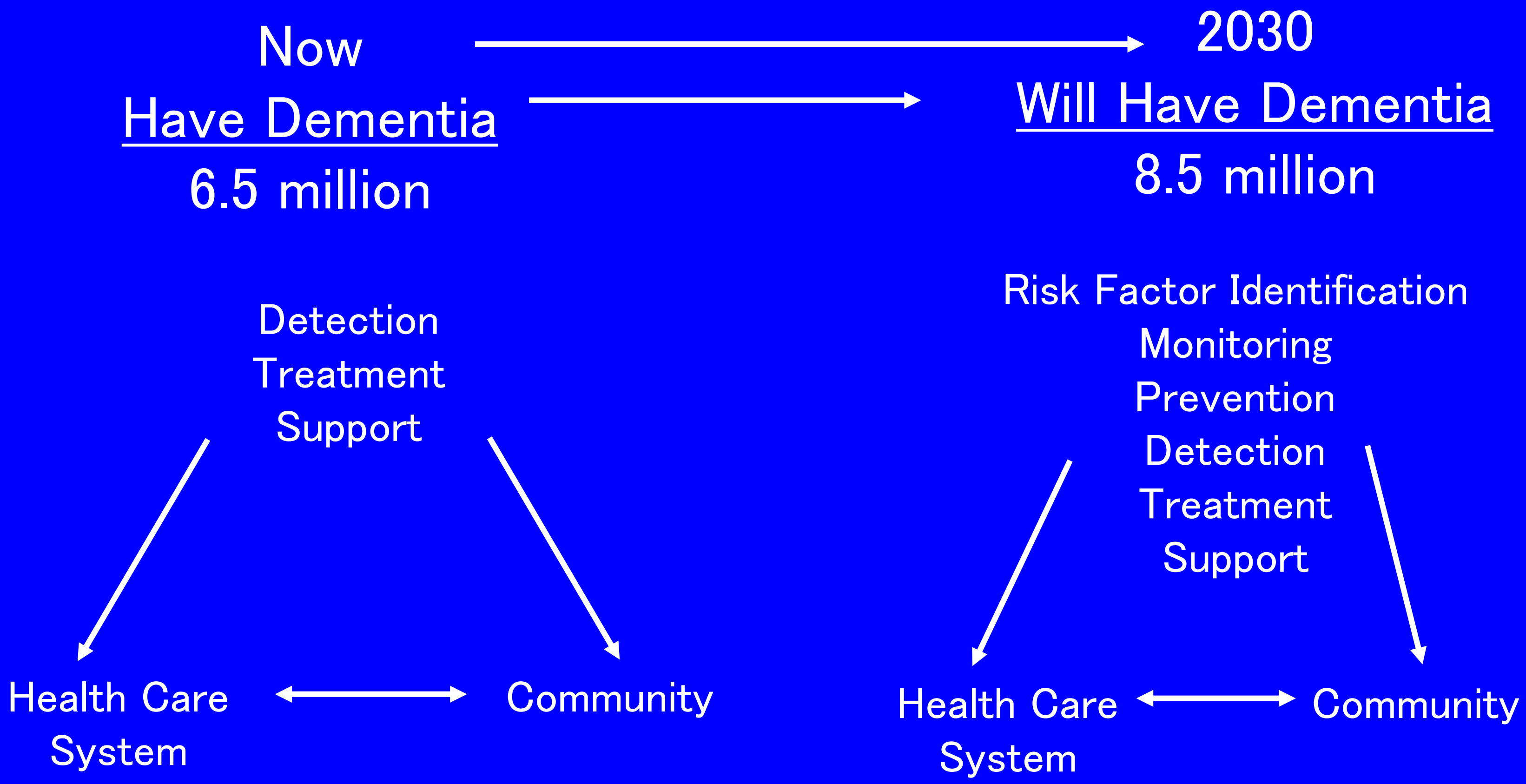
- * Based on medical record abstraction

Jennings LA, et al. J Am Geriatr Soc, Jun 2016. PMID: 27355394

Natural History and Complications

- Progression of cognitive decline
  - 3–4 points on MMSE/year
- Non-cognitive symptoms
  - Apathy (~50%)
  - Depressive symptoms (~40%)
  - Agitation or aggression (~40%)
  - Sleep disorder (~40%)
  - Delusions (~30%)
- AD survival after symptom onset 3–12 yrs; other dementias have worse survival

Alzheimer’s Disease: A Two-Phase Strategy



Now

Have Dementia

6.5 million

2030

Will Have Dementia

8.5 million

Detection
Treatment
Support

Health Care System

Community

Risk Factor Identification
Monitoring
Prevention
Detection
Treatment
Support

Health Care System

Community

Management

- This is a lifelong disease
- Play the ball where it lies
  - If disease is early, include PLWD
  - If late, rely on family and caregiver
- Aim for the highest level of independence that works for everyone
- Treat the disease
- Manage hot-button issues (e.g., driving)
- Manage other diseases
- Manage symptoms

Caregiver Support

- Caregivers are the most important resource
- Over 50% of caregivers develop depression
- The more knowledgeable and empowered the caregiver is, the better the care
- Caregiver training/support programs
  - REACH II (12 individual and 5 telephone support groups over 6 months) improves depression at 6 m
  - NYU CI (2 individual counseling sessions, 4 family counseling sessions, weekly support groups, ad-hoc counseling)
  - Alzheimer's Association and other community resources

Caregiver Support

- Evidence: small to moderate effect on:
  - Knowledge, Well being, Confidence/self-efficacy
  - Time to institutionalization
  - Behavioral symptoms
- Barriers and limitations
  - Focus only on the caregiver
  - Tested using traditional research not pragmatic designs
  - Cost ($2.50-$5/day for 6 months)
  - Poor integration with health care systems

New Models of Comprehensive Care for Dementia

- Focus on patient and caregiver
- Community-based
  - BRI Care Consultation
  - MIND at Home (Hopkins)
  - The Care Ecosystem (UCSF)
- Health System-based
  - Indiana University Healthy Aging Brain Center (HABC)
  - The UCLA Alzheimer's and Dementia Care Program
  - Integrated Memory Care Clinic (Emory)

Elements of Comprehensive Dementia Care

- All have:
  - Continuous monitoring and assessment
  - Ongoing care plans
  - Psychosocial interventions
    - Aimed at person living with dementia
    - Aimed at caregivers
  - Self-management
  - Medication management (some comm-based don’t)
  - Treatment of related conditions
  - Coordination of care

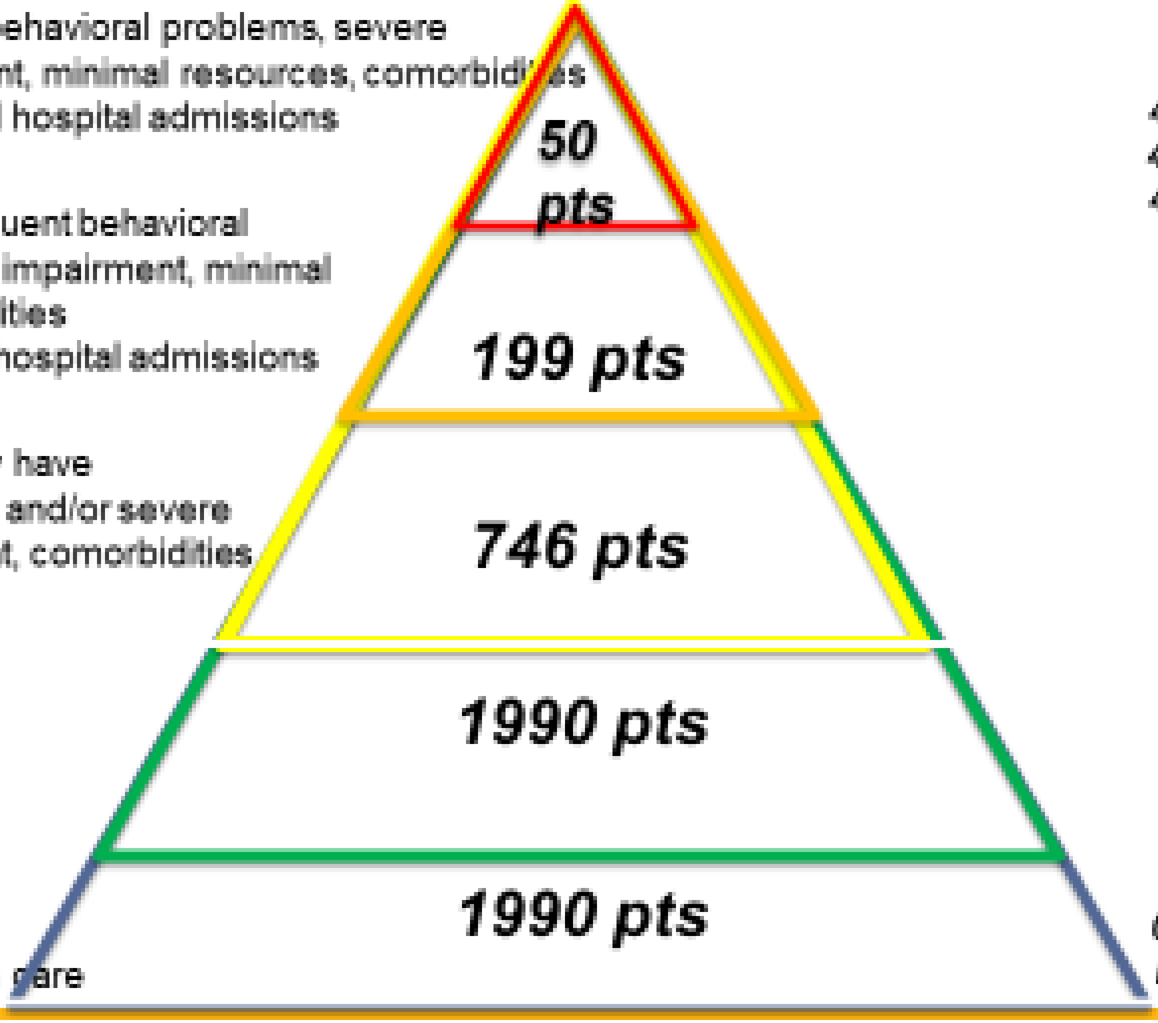
Comparison of Some Dementia Care Models

	BRI CC	Care Ecosystem	MIND	HABC	UCLA ADC	IMCC
Structure/process						
Key personnel	SW, RN, MFT	Non-licensed APN, SW, Pharmacist	Non-licensed RN, MD	Non-licensed MD, SW, RN, Psychologist	NP, PA, MD	APN
Key personnel base	CBO	Community	Community	Health system	Health system	Health system
Face-to-face visits	No	No	Yes	Yes	Yes	Yes
Access 24/7/365	No	No	No	Yes	Yes	Yes
Communication with PCP	Mail, fax	Fax, phone	Phone, mail, fax	EHR, phone, mail	EHR, phone	N/A
Order writing	No	No	No	Yes	Yes	Yes
Benefits						
High quality of care	N/A	N/A	N/A	Yes	Yes	Yes
Patient benefit	Yes	Yes	Yes	Yes	Yes	NS
Caregiver benefit	Yes	Yes	Yes	Yes	Yes	NS
Costs of program	++	++	+++	+++	++++	++++
Cost savings, gross	++	++	None	++	++++	++++

Barriers to Dissemination

- Inertia and lack of insight
- Costs:
  - Occur up-front while savings are downstream
  - Insufficient revenue
  - Savings may accrue to different stakeholders
- Training of providers
- Community-based partners
  - Identification and vetting
  - Payment

2017 Population-based Dementia Care Model
5,000 patients



Risk Stratification		Utilization
1st Tier (1%) Many behavioral problems, severe functional impairment, minimal resources, comorbidities - Frequent ED and hospital admissions	***50 pts***	***$186,000*** ***49 Bed Days*** ***4.8 ICU Days*** ***4.7 ED Visits***
2nd Tier (2-5%) Frequent behavioral problems, functional impairment, minimal resources, comorbidities - Multiple ED and hospital admissions	***199 pts***	***$65,000*** ***17 Bed Days*** ***0.6 ICU Days*** ***3.6 ED Visits***
3rd Tier (6-20%) May have behavioral problems and/or severe functional impairment, comorbidities	***746 pts***	***$20,000*** ***4.6 Bed Days*** ***0 ICU Days*** ***1.8 ED Visits***
4th Tier (21-60%) - Mild dementia - Getting routine health care	***1990 pts***	***$1,000*** ***0 Bed Days*** ***0 ICU Days*** ***0.4 ED Visits***
5th Tier (61-100%) - Mild dementia - Getting no health care	***1990 pts***	***$0*** ***0 Bed Days, ICU Days, ED Visits***

UCLA Health

Total # & Yearly Minimum Utilization By Risk Tier

Population-based Dementia Care Model

Risk Stratification

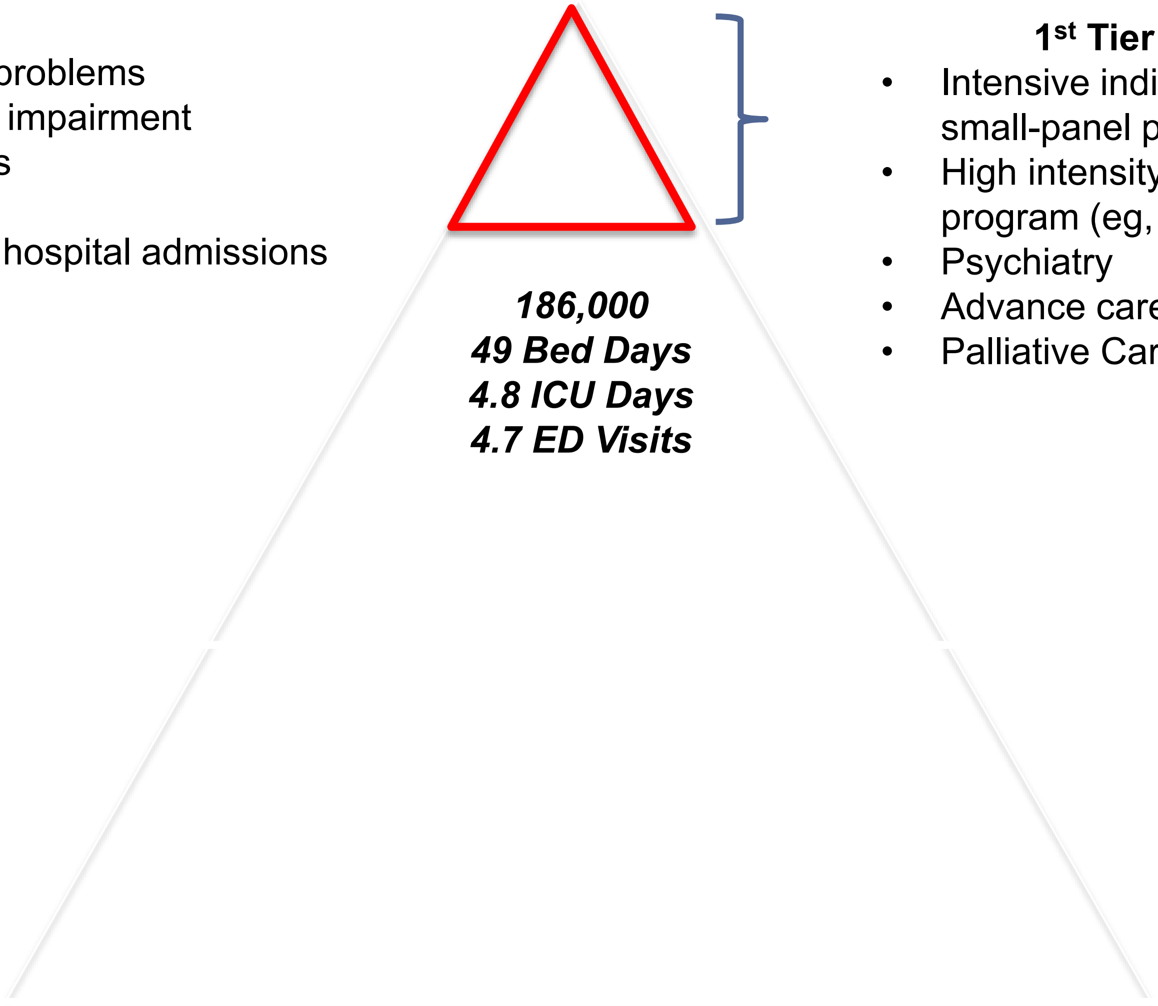
1st Tier (1%) *50 pts*

- Many behavioral problems
- Severe functional impairment
- Minimal resources
- Comorbidities
- Frequent ED and hospital admissions

Dementia Plan of Care

1st Tier (1%) 50 pts

- Intensive individualized care, small-panel primary care
- High intensity Dementia Care program (eg, UCLA ADC, IMCC)
- Psychiatry
- Advance care planning
- Palliative Care



186,000
49 Bed Days
4.8 ICU Days
4.7 ED Visits

Total # & Yearly Minimum Utilization By Risk Tier

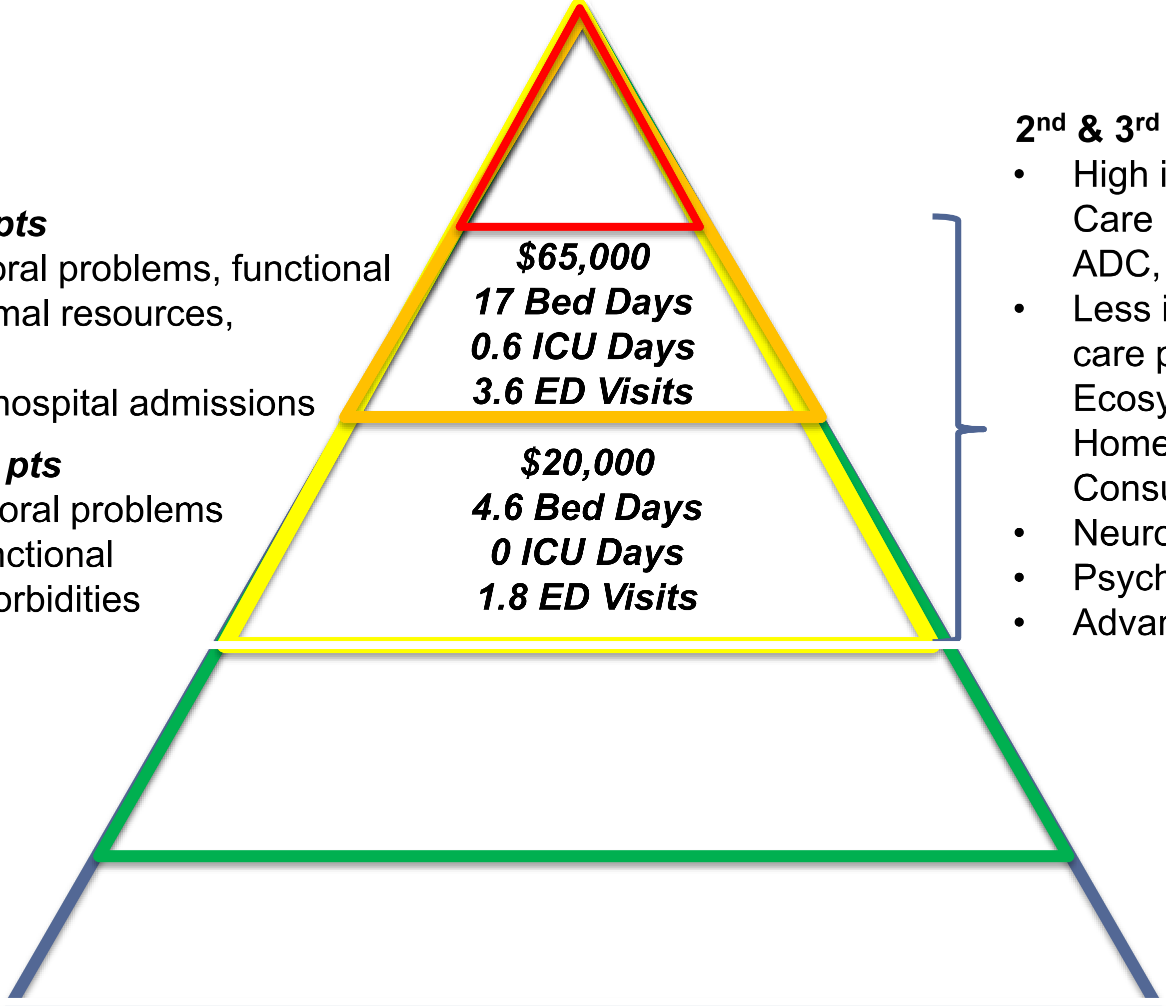
Population-based Dementia Care Model

Risk Stratification

Dementia Plan of Care

2nd Tier (2-5%) ***199 pts***
- Frequent behavioral problems, functional impairment, minimal resources, comorbidities
- Multiple ED and hospital admissions

3rd Tier (6-20%) ***746 pts***
- May have behavioral problems and/or severe functional impairment, comorbidities



$65,000
17 Bed Days
0.6 ICU Days
3.6 ED Visits

$20,000
4.6 Bed Days
0 ICU Days
1.8 ED Visits

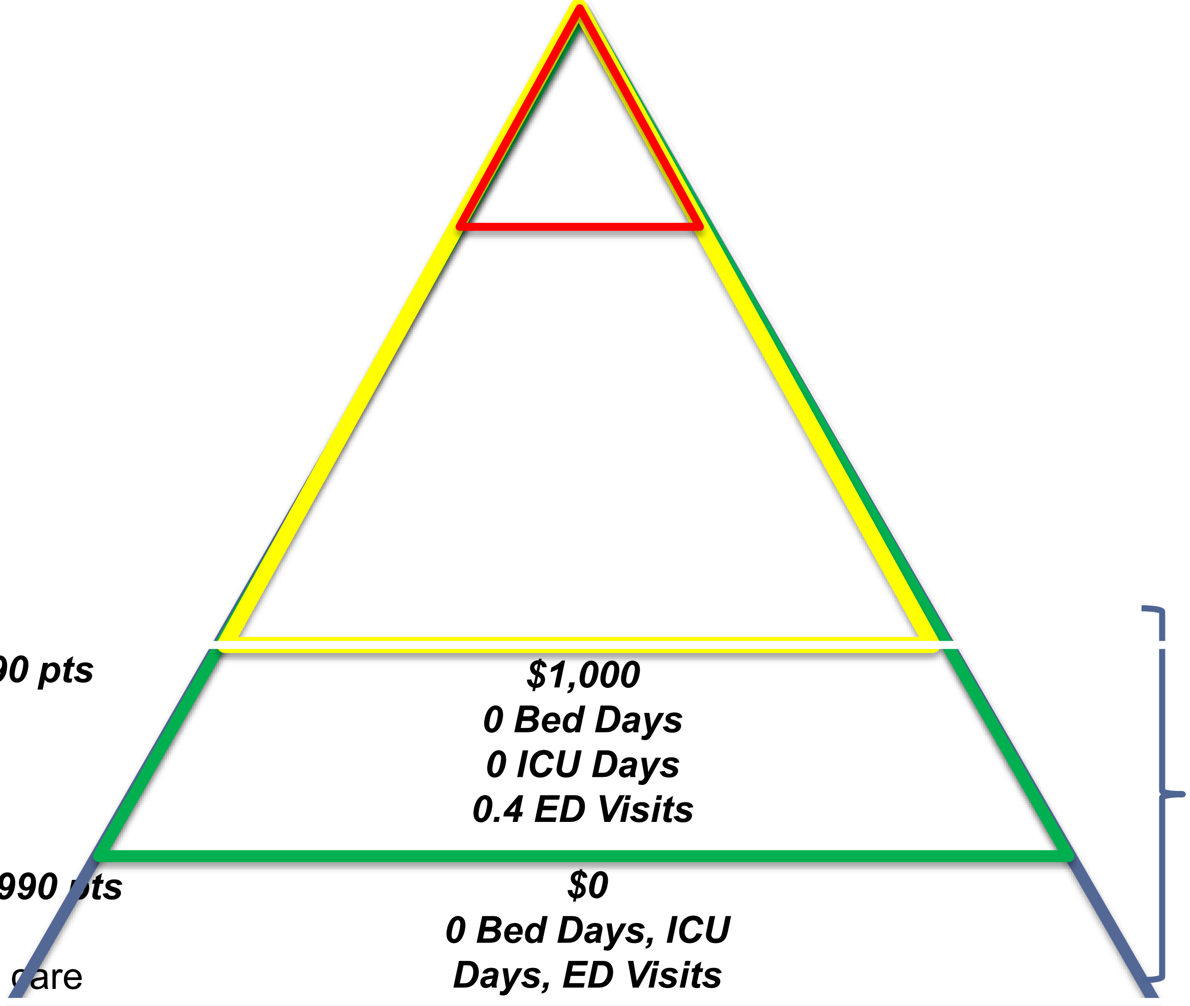
2nd & 3rd Tier (2-20%) 945 pts
- High intensity Dementia Care program (eg, UCLA ADC, IMCC, HABC)
- Less intensive dementia care program (eg, Care Ecosystem, MIND at Home, BRI Care) Consultation
- Neurology
- Psychiatry
- Advance care planning

Total # & Yearly Minimum Utilization By Risk Tier

Population-based Dementia Care Model

Risk Stratification

Dementia Plan of Care



4th Tier (21-60%) ***1990 pts***
- Mild dementia
- Getting routine health care

5th Tier (61-100%) ***1990 pts***
- Mild dementia
- Getting no health care

$1,000
0 Bed Days
0 ICU Days
0.4 ED Visits

$0
0 Bed Days, ICU Days, ED Visits

4th & 5th Tier (21-100%) 3,9
- Less intensive dementia care program
- Information and referral
- Caregiver education,
- Monitoring and usual care

Total # & Yearly Minimum Utilization By Risk Tier

One Final Thought: What Are We Aiming For?

Disease-based Outcomes

- Disease-specific
- Medical outcomes
  - Survival, Biomarkers
  - Disease-specific symptoms
- Population health goals
  - Universally applied
- For persons with a single chronic disease or longer life expectancy
- Can be person-centered; may not capture what is most important to the person

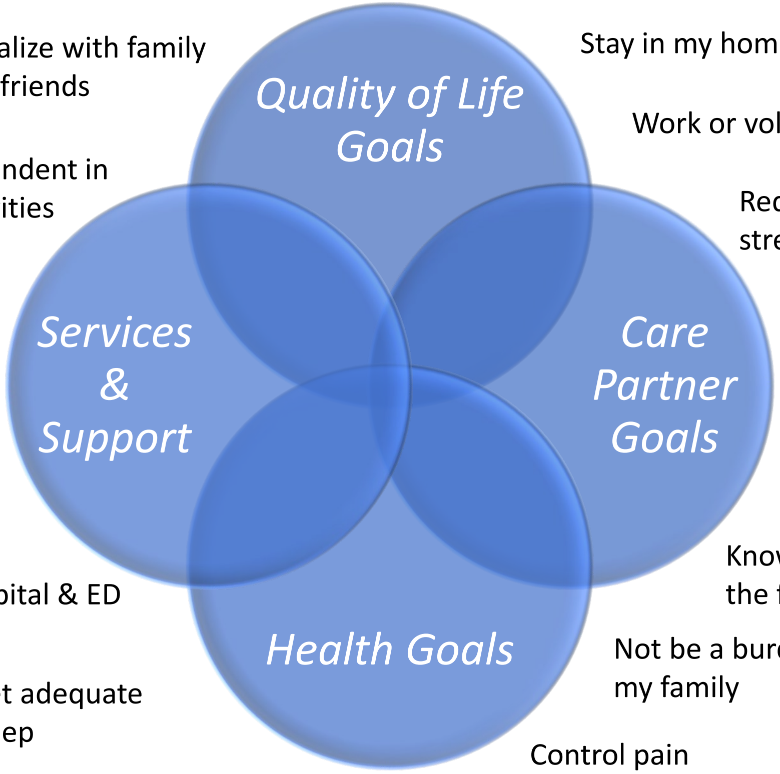
Person-defined Outcomes

- Span conditions
- Medical & non-medical outcomes
  - Functional independence
  - Social interaction
- Personal health goals
  - Individually determined
- For persons with multiple chronic conditions, limited life expectancy, or specific disabling diseases
- Always person-centered

Reuben DB, Tinetti ME. NEJM 2012;366(9):777-779.

What matters most?

Findings from Focus Groups with Persons with Dementia and their Care Partners



Quality of Life Goals

Services & Support

Care Partner Goals

Health Goals

Socialize with family and friends

Be independent in daily activities

Have respite care available

Have end of life plans in order

Stay out of the hospital & ED

Get adequate sleep

Decrease falls

Control pain

Not be a burden to my family

Know what to expect in the future

Maintain caregiver’s health

Minimize family conflict

Reduce caregiver stress

Work or volunteer

Stay in my home

Jennings LA, et al. Quality of Life Research.2017;26(3):685-93.

RESEARCH SUMMIT ON DEMENTIA CARE
Building Evidence for Services and Supports

#DementiaCareSummit

#1 Goal at Baseline, Total N=101

Type of Goal	n
Caregiver Support	34
Patient Quality of Life - Physical	30
Patient Quality of Life - Social & Emotional	16
Patient Medical Goals	14
Patient Goals for Accessing Services & Support	7

Commonly Selected Top (# 1) Goals

Goal, N=133	N (%)
Medical Care	
Stays out of the hospital	7 (5%)
Receive needed dementia care	8 (6%)
Patient Quality of Life	
Is physically safe	20 (15%)
Is physically active	6 (4.5%)
Is able to live at home	11 (8%)
Keeps mind stimulated	6 (4.5%)
Accessing Dementia Services	
Has adequate caregivers	4 (3%)
Caregiver Support	
Maintain caregivers’ health	15 (11%)
Caregiver able to deal with stress	7 (5%)
Minimize family conflict in dealing with dementia	5 (4%)

Thank you