

# Experiences of Diverse Older Adults Living with Dementia

November 16<sup>th</sup>, 2022



#### Welcome from...



#### Joseph E. Gaugler, PhD

Director, BOLD Public Health Center of Excellence on

Dementia Caregiving

Professor and Robert L. Kane Endowed Chair in Long-Term

Care & Aging, University of Minnesota

His research examines innovation in dementia care.



#### Land acknowledgement

The University of Minnesota Twin Cities is located on traditional, ancestral, and contemporary lands of Indigenous people. We acknowledge with gratitude the Land itself and the People. We take to heart and commit through action to learn and honor the traditional cultural Dakota Values: Courage, Wisdom, Respect and Generosity.



## The BOLD Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC)

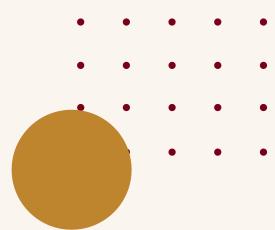
Designed to support state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives, by...



Improving access to evidence-based programs and best practices.



Facilitating connections and collaboration among public health agencies and a wide range of service organizations.





Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies.



#### Health Equity Task Force (HETF)

The HETF team works across the Center to ensure health equity is centered in our programming, resources, and leadership.



Helps the Center and its partners identify, develop and disseminate culturally tailored and caregiver-centered materials, tools and support to public health stakeholders,



Provides feedback on the Center's engagement strategies to ensure the inclusion of diverse and minority-serving stakeholders, etc.



Jason Resendez



Lauren Parker, PhD



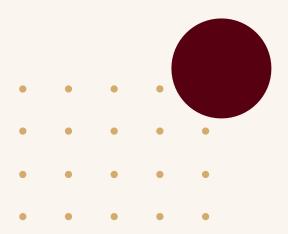
Ocean Le, MS



Fayron Epps, PhD, RN, FAAN



#### Welcome panelists!



#### Ocean Le, M.S.

Program and Communications Manager, Diverse Elders Coalition

#### **Andrea Robert**

Person Living with Mild Cognitive Impairment

#### Kevin T. Britton II, Esq.

Caregiver & Associate, Dorsey & Whitney LLP

#### **Dave Baldridge**

Executive Director of the International Association for Indigenious Aging

#### **Ginny Biggar**

Executive Director of Communities, UsAgainstAlzheimer's

#### **Moderator:**

#### Chelsea Kline, MPH

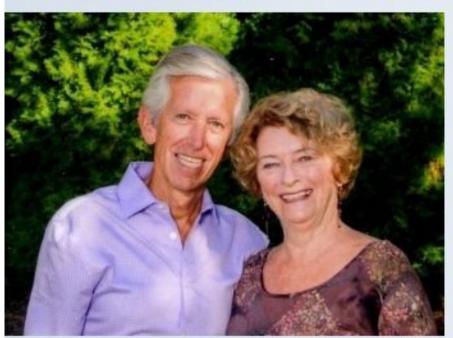
Associate Director of PHCOE on Risk Reduction, Alzheimer's Association



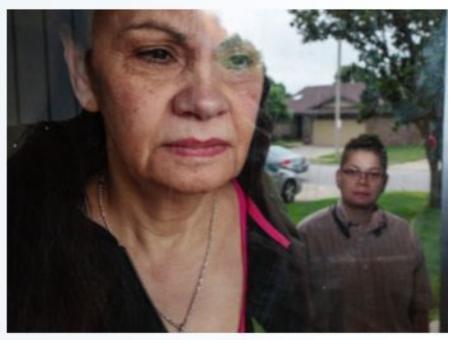




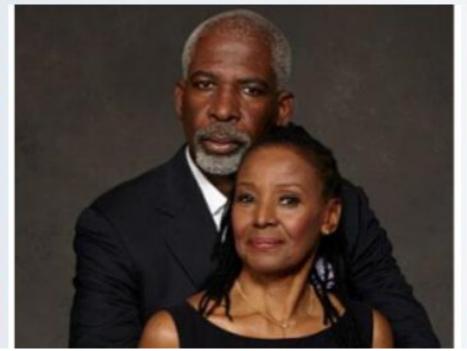


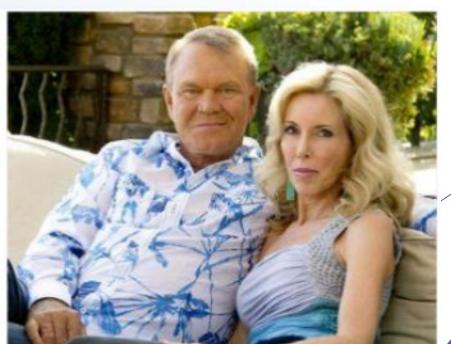












#### UsAgainstAlzheimer's

- Early Intervention to improve brain health, promote earlier detection, diagnosis and intervention
- Health Equity & Access for people disproportionately impacted
- Speeding Treatments by advocating for increased research spending
- Voices of Alzheimer's to drive change that matters most
  - ☐ What Matters Most research program: *A-LIST*



#### A-LIST

- Online registry: 10,000+ members
- What Matters Most Insights study: monthly surveys
- Topics: ADRD journey
- Values: Longitudinal, rapid response data
- Values: Commitment to members and ethical oversight
- Results: Inform public health, policy, research, healthcare leaders



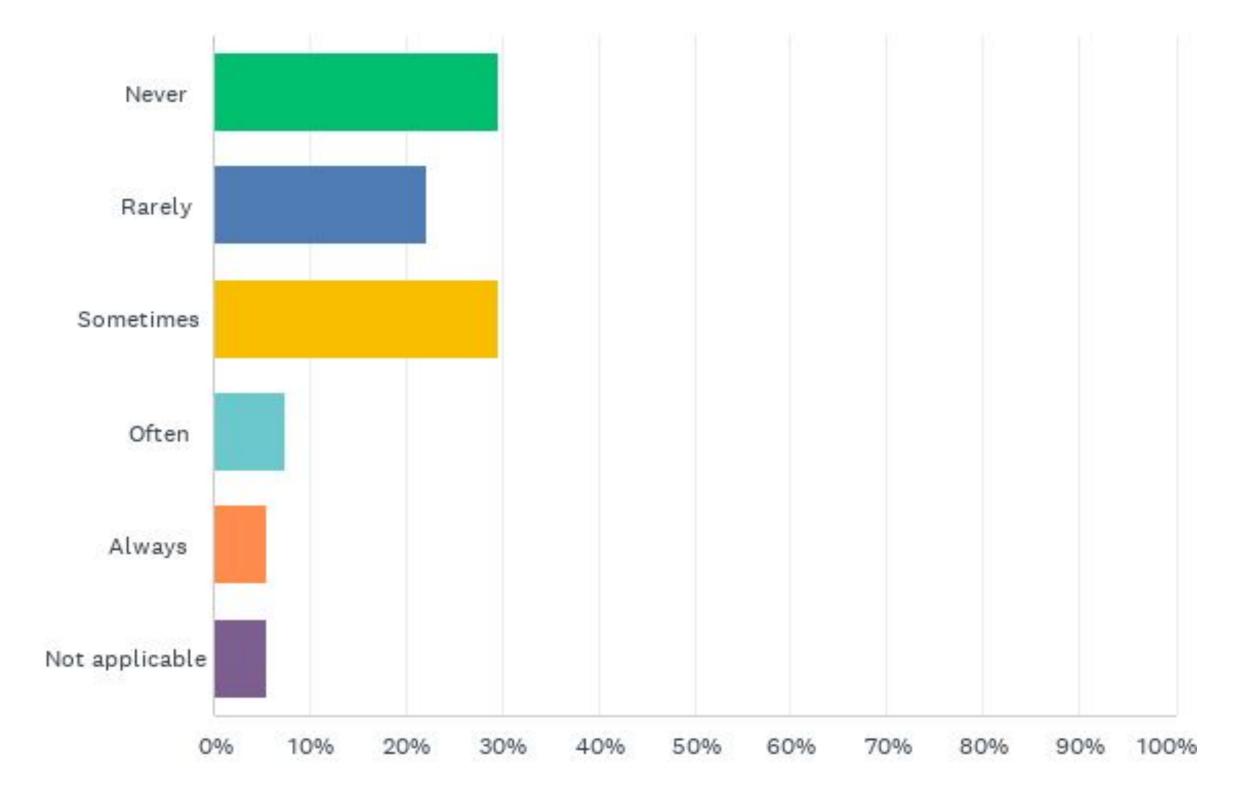
### Survey: Attitudes toward Dementia

- Living with ADRD: Relatively modest stigma mostly related to feeling left out of things, seeing that people are uncomfortable with them, and embarrassment about their illness and physical limitations
- Caregivers: More types of stigma than other groups. Many observed that care recipient is treated differently by family, health care providers and others. Believed that diagnosis either has or will affect the person with dementia's ability to function as a spouse, parent, or grandparent.
- Brain Health Interested/at Risk for ADRD: Had positive feelings about people with dementia and working with them.
- **N**= 682



## Results: Living with ADRD/MCI (N=59)

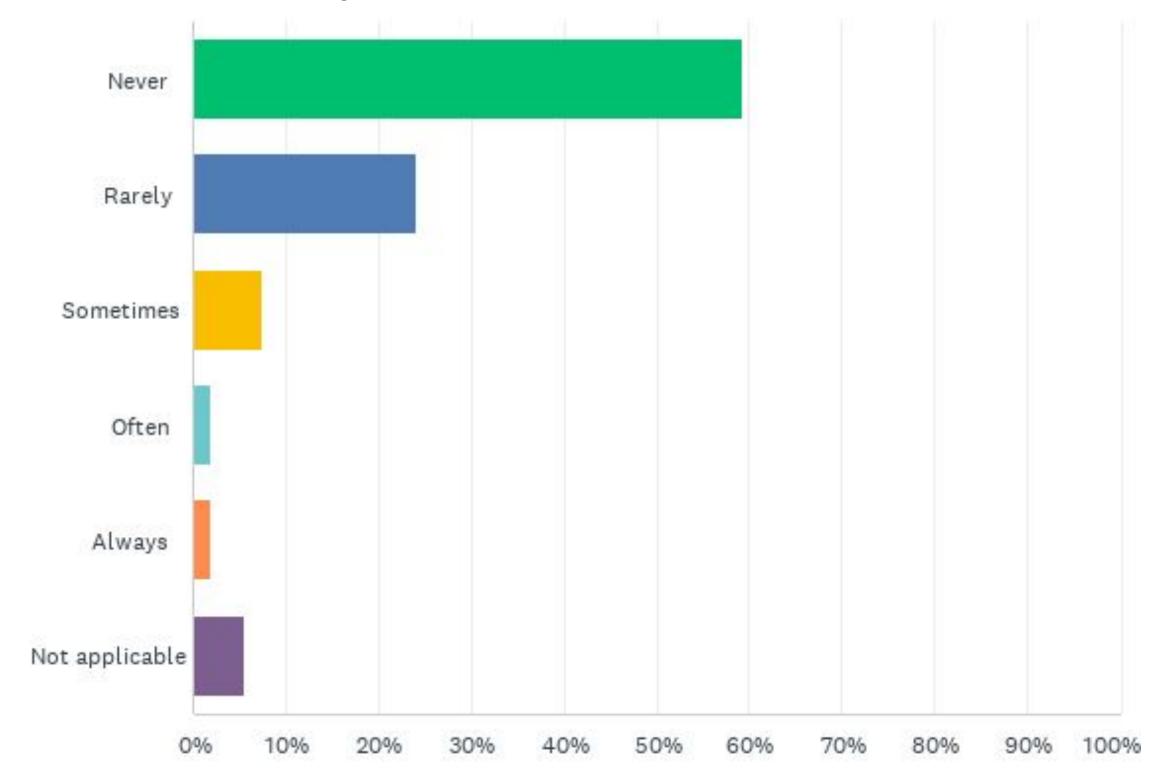
Q: Because of my illness, I feel left out of things:





## Results: Living with ADRD/MCI

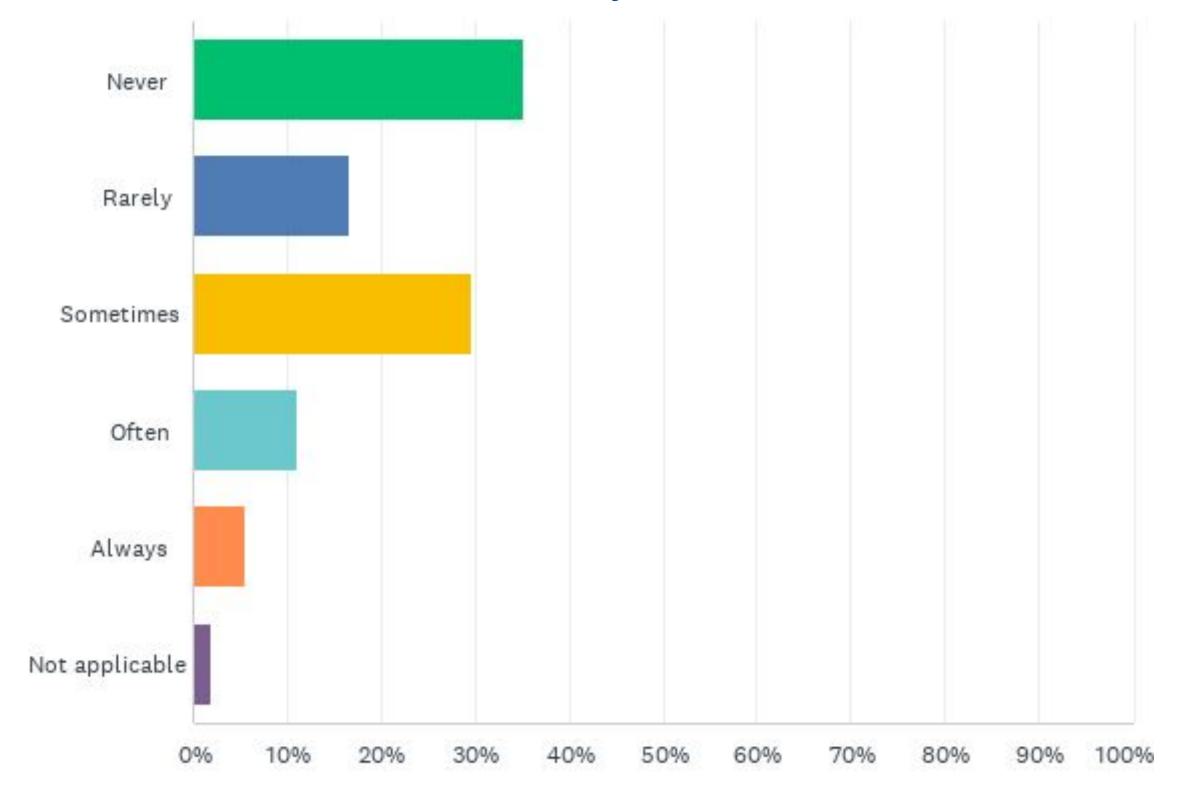
Q: Because of my illness, people are unkind to me:





## Results: Living with ADRD/MCI

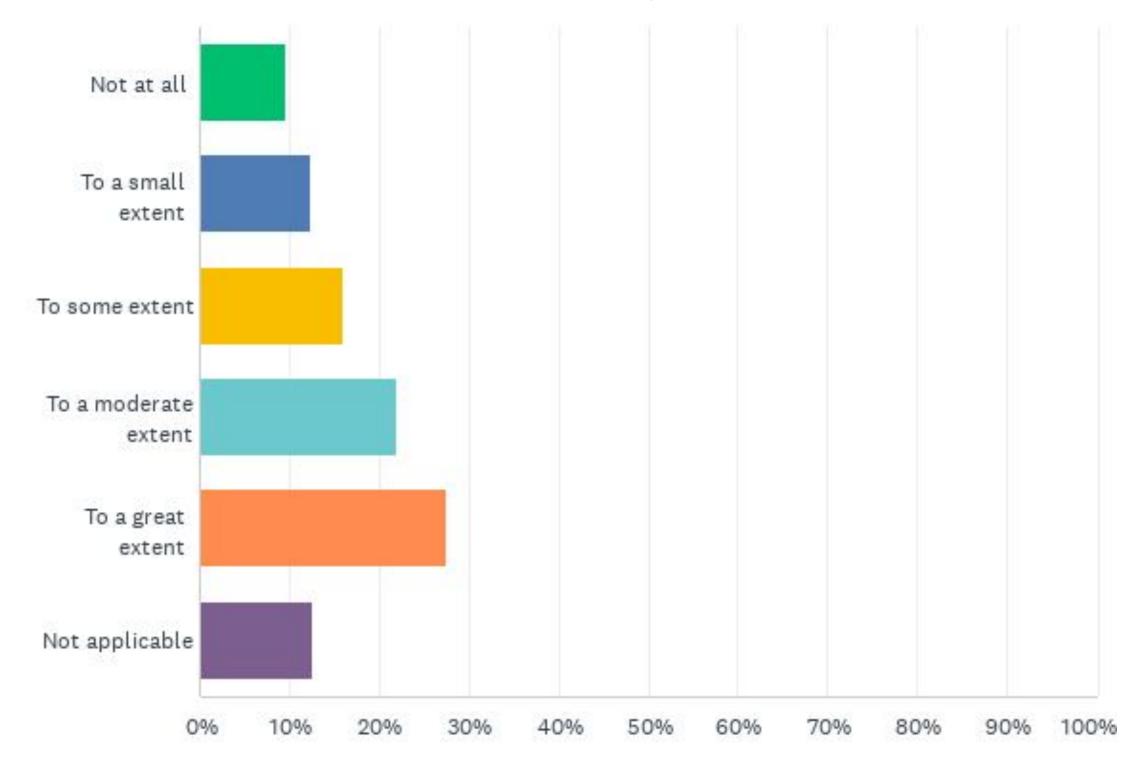
Q: I feel embarrassed about my illness:





## Results: Caregivers (N=377)

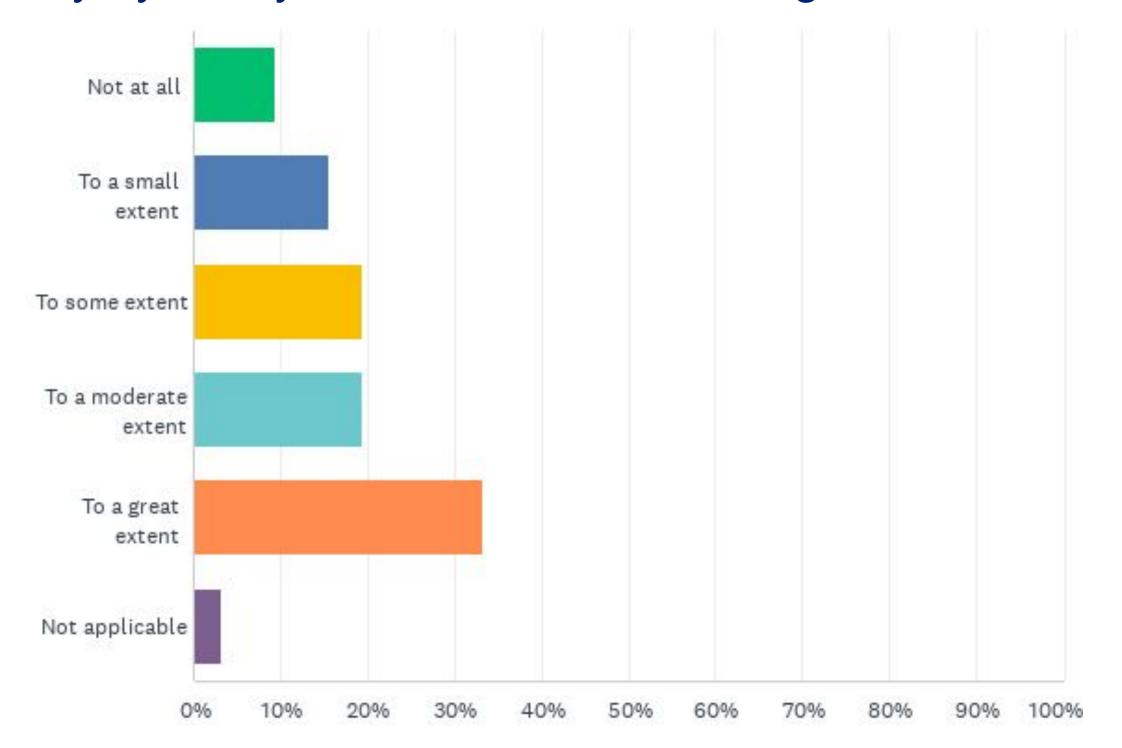
Q: To what extent do/did you experience a reduction in your social contacts after the diagnosis?





## Results: Caregivers

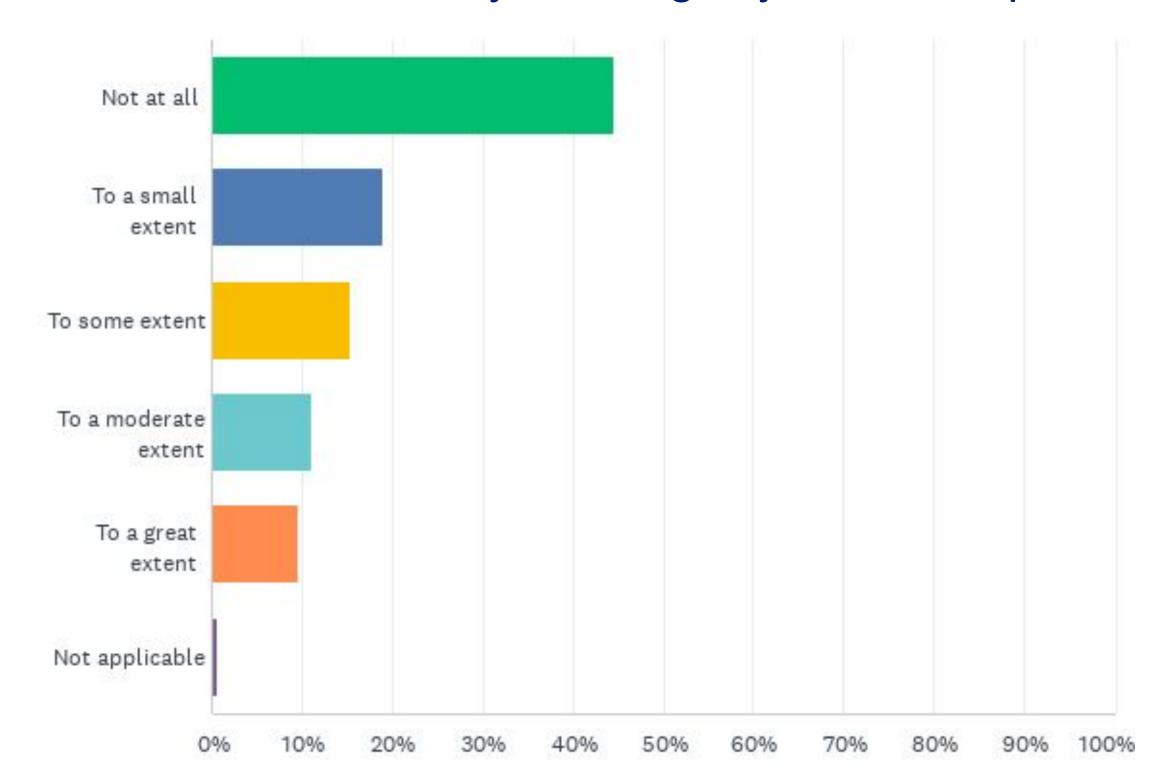
Q: To what extent do/did you feel that the person is treated differently by family members since the diagnosis?





## Results: Caregivers

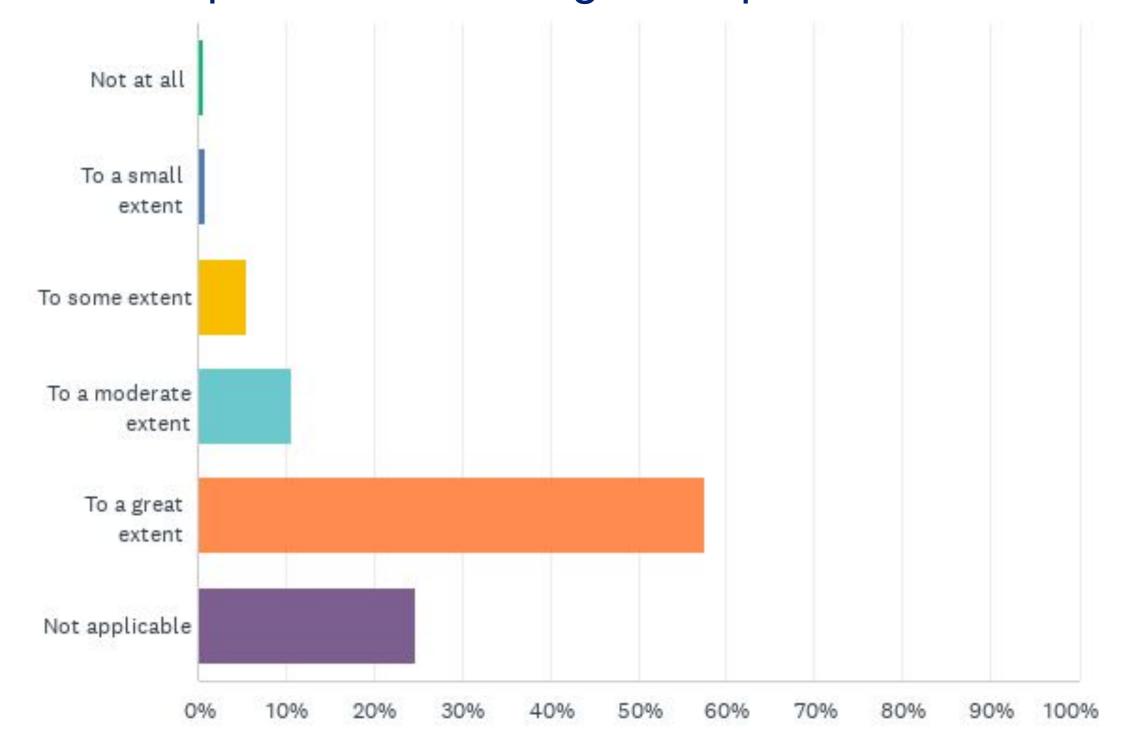
Q: To what extent do/did you feel guilty about the person's situation?





## Results: Caregivers

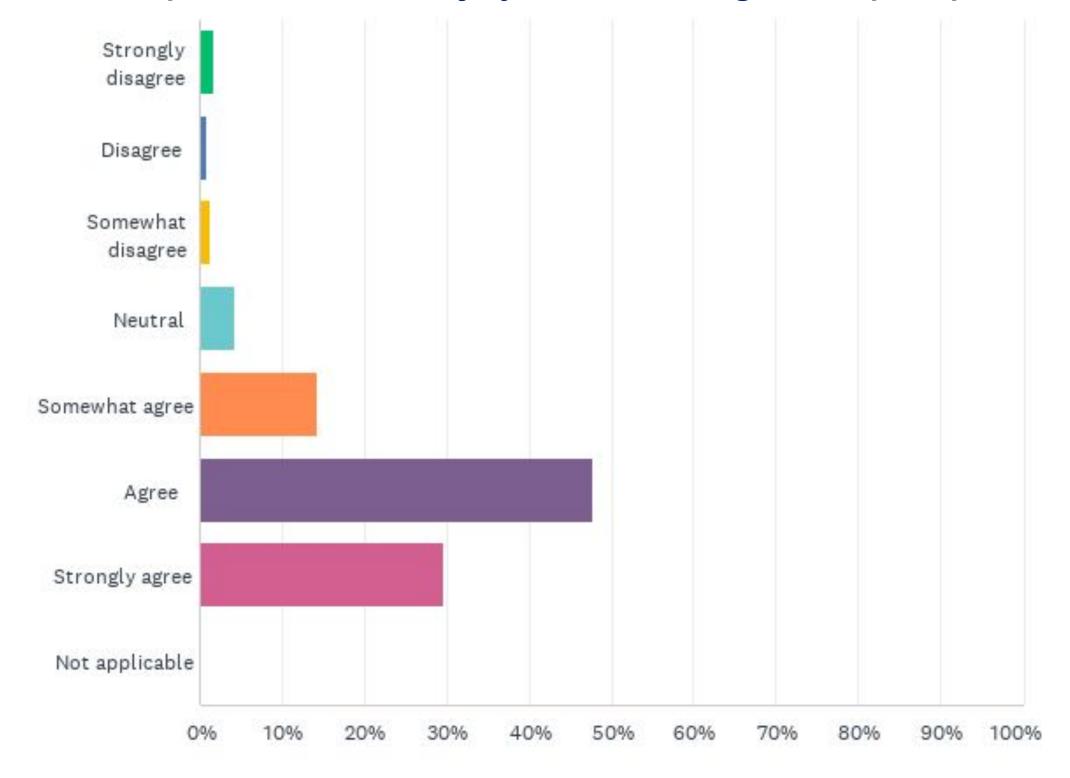
Q: To what extent do/did you think that the diagnosis will/did affect the person functioning as a spouse?





## Results: Interested in Brain Health/At Risk (N=246)

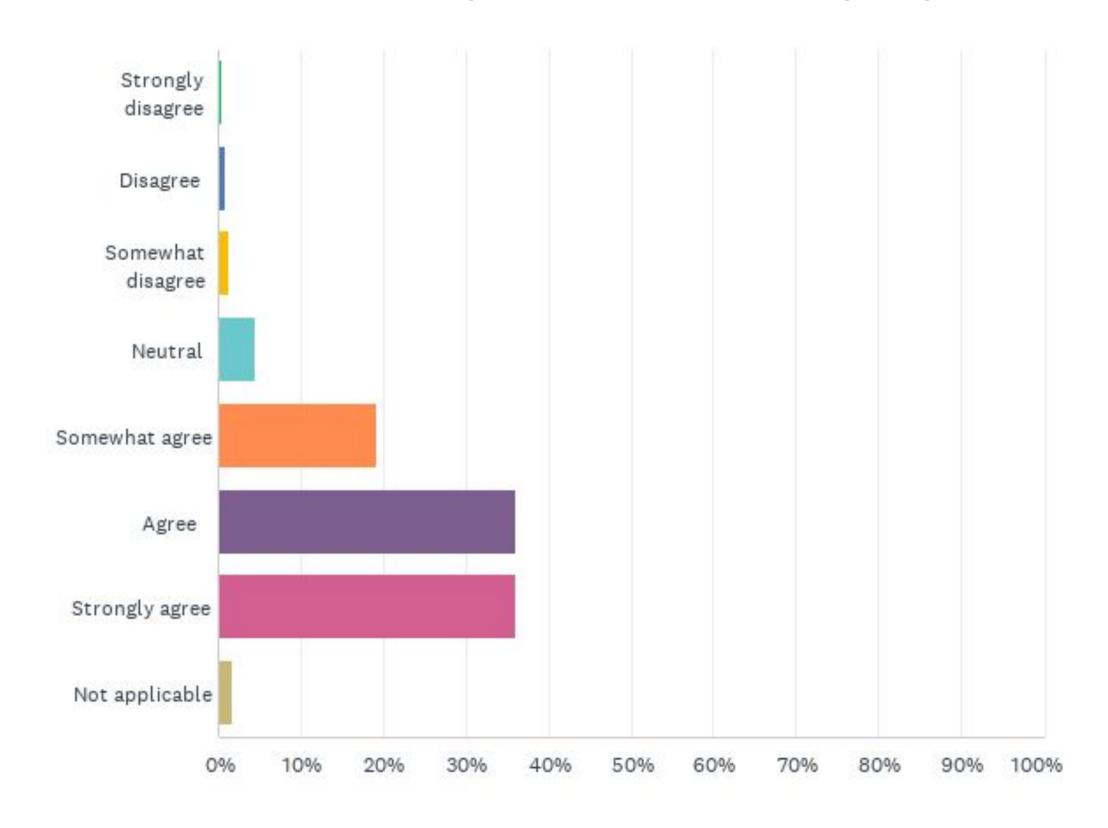
Q: It is possible to enjoy interacting with people with dementia.





#### Results: Interested in Brain Health/At Risk

Q: We can do a lot now to improve the lives of people with dementia.





## Q&A

Please, submit your questions in the Q&A Zoom feature!



#### **Future Events**

#### **January**

- RAISE National Strategy Webinar
- Successful Public Health Approaches in Dementia Caregiving:
   A Virtual Roundtables Series

#### **February**

 Dementia Caregiving Topics in Public Health: A Virtual Roundtable Series



#### Connect with us!

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- ✓ Find today's slides and recording.
- ✓ Request Technical Assistance to support your public health work in dementia caregiving.
- ✓ Access resources and materials.
- Stay up to date with PHCOE-DC activities.

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