



PRESENTER

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National Council of Dementia Minds (NCDM), first national non-profit founded and governed by persons living with dementia.

NATIONAL COUNCIL OF DEMENTIA MINDS



In Our Own Words: Transforming Life with Dementia

Background

- Groundbreaking approach with individuals living with dementia as co-authors and co-researchers.
- Provides recommendations regarding information and resources for persons living with dementia from the date of diagnosis to one year thereafter.

Needs Assessment Approach

- 65 participants living with various types of dementia
- Across 10 focus groups including individuals representing Black, Latino, LGBTQ+ communities, persons living with young-onset dementia and physicians.
- All participated in 3 focus groups focused on: actual resources received from diagnosis to 1 year after and desired resources.
- The physician's group participated in 4 focus groups.



AGE OF STUDY PARTICIPANTS

Diagnoses

22	Alzheimer's Disease
20	Mild Cognitive Impairment
12	Frontotemporal Dementia
10	Lewy Body Disease
6	Vascular Dementia
2	Posterior Cortical Atrophy
2	Chronic Traumatic Encephalopathy
5	Unspecified Dementia



Recommendations

- **Establish a Disease Management Protocol** akin to those used for other chronic conditions like diabetes, heart disease, or cancer, tailored specifically for individuals diagnosed with dementia.
- **Establish Peer Support Groups for Individuals Living with Dementia** to actively learn and exchange strategies for living well with dementia. Groups should meet the unique needs of people living with dementia by establishing culturally specific support groups (i.e. Black, Latinos, LGBTQ+, Young-Onset).
- **Develop and Implement Comprehensive Communication Training for Doctors** regarding interactions with individuals living with dementia. Train doctors to recognize and respect the capabilities and competence of individuals living with dementia, avoiding assumptions of incapacity.
- **Provide Access to an Interdisciplinary Team of Professionals** including case coordinators for medical services, psychologists or counselors, social workers, nurse practitioners, elder law attorneys, etc.. Provide resources with diagnosis-specific information including dementia progression, financial planning recommendations, and available government benefits (i.e. Social Security Disability Insurance, Medicare, etc).

“I know for me the more I learned about my disease, the less scary it became.”

“I began attending a support group every week. I know that was the most valuable thing I found. I didn't have another appointment with my neurologist for 3 months. When I was ready to go back to this neurologist, I had 3 pages of questions to ask.”



Full Report