

The Who, What, Why, When and Where of Care Partners in Research

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Family Caregiver Stakeholder Group



#DementiaCareSummit

Who? Dementia affects everyone



Care Partners

Spouses
Care workers
Family



Those living with dementia

Frontotemporal Degeneration
Alzheimer's
Over 100 other dementias



Families

Children
Grandchildren
Parents
Siblings

All Photos in this presentation represent families living with frontotemporal degeneration

What? Needs are great



Day Programs

- Staying engaged
- Age appropriate and skill appropriate
- Educated work force



Care Partner Relief

- Rest for care partners
- Affordable options
- Not impoverishing spouses for their future



Engagement

- Activities
- Public awareness
- Using skills

Why? Because they deserve better



Age matters

- Appropriate activities
- Affordable for young families
- Protection against expelling younger, stronger populations from care facilities



Interests matter

- Staying engaged
- Creating opportunities
- Pairing volunteers to those who share interests



Inclusion matters

- Being involved in public
- Public awareness campaigns to reduce stigma

When? Now



No time to lose

Research to reality times need to be reduced

Needs increase rapidly

Education of dementia workforce on dealing with behaviors



Public awareness

Dementia friendly cities

Media coverage

Public Service Announcements to remove stigma



Aging in place

Resources to stay in home

Support for care partners giving care

Understanding care partner stress and resources needed for care

Where? Everywhere



Education

Everyone involved from doctors, bankers, attorneys and those working in care

Addressing ALL dementia

Standards of memory care



Accessibility

Continuity from state to state, Medicare not Medicaid

Urban and rural

Physicians who understand palliative care



Affordability

Federal standards of memory care facilities

Published rates

Medicaid waivers for young population



www.DementiaNeeds.blogspot.com

Visit this site for more detailed information on the needs of those living with dementia, their care partners, and families.