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

Sharon Hall
Family Caregiver Stakeholder Group

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
When you're a care-partner for a loved one living with dementia...

You lose pieces of your heart every single day.

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