Work With Us! We Want to Help!
Perspectives of a Person with Dementia on Involvement as a Study Partner

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RESEARCH SUMMIT ON
DEMENTIA CARE
Building Evidence for Services and Supports

#DementiaCareSummit

Dedicated to my mom: Claire Matthews Huling who died of Alzheimer's on April 4, 2014

Resource PCP's to Resource Patients

• *Provide resources on research opportunities to primary care providers, social workers, and other health care professionals so that they can share this information with patients (and families) as part of dementia care management.*

Demystify the Process

• *Present information including risks and benefits, consent forms written in easy to understand language.*

• *Use different formats to reach potential recruits for example: Make a video about your study and why it is important*

• *Avoid complicated scientific/medical jargon.*
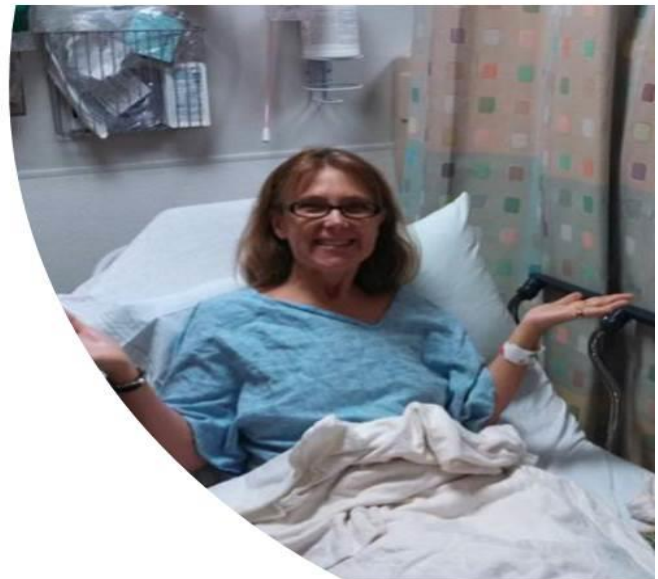
Think Outside of the Box To Reduce Obstacles to Participation

- *Send Researchers into the field (think bookmobile).*
- *Use technology such as Skype and Zoom to communicate with persons with dementia in your study.*
- *If a study partner is mandated, be flexible in scheduling appointments so the study partner can come.*
- *If a family member is not available, consider interviewing a friend, neighbor, pastor, rabbi, or someone else who knows the person well.*

Research Recommendation: Do Non-Medic

Please do non-medical studies that focus on psychosocial care practices and behavioral strategies to address neuropsychiatric symptoms including hallucinations, emotional issues (depression, anger), and information processing challenges (i.e. noisy environments) as well as other problematic symptoms such incontinence and impaired motor control affecting balance and risk for falls.

Some Live Alone: Help us to Maintain Our Independence!

Please do research on the experience of living independently and adjusting to life with a cognitive disorder, and the implications of living without an identified care partner/caregiver or access to person(s) assuming the role.

We want to work with you.
We want to help!