

## Phase 1: Initial Team Meeting Discussion Guide

### TEAM MEMBER INTRODUCTIONS / PROJECT OVERVIEW

- Could include: name, organization, role, what they hope to get out of participation in the project.
- Be sure to highlight any team members that have recently joined if you've added additional organizations/people to your team.
- **Project Overview:** Describe what is known about the scope of dementia in your community. Share a general vision of what your community team is hoping to accomplish. Share a personal story about dementia to ground and engage attendees.

### REVIEW / DISCUSS DEFINITIONS

**Dementia** is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities.\*

#### Types of Dementia\*

**Alzheimer's disease** is the most common type of dementia (60-80% of cases) that causes problems with memory, thinking and behavior. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks.

**Vascular dementia** affects judgment, decision making, and physical functioning and is caused by damage to blood vessels resulting in brain injury.

**Lewy body dementia** has similar symptoms to Alzheimer's disease but often begins with disturbances to sleep, hallucinations, muscle rigidity and Parkinson's-like movement

**Mixed dementia** is the occurrence of more than one form of dementia occurring simultaneously. Recent studies show that is more common than once believed

**Parkinson's disease** progression can often result in symptoms similar to Lewy body dementia or Alzheimer's disease

**Frontotemporal dementia** generally affects people at younger ages and causes change in personality, behavior, and difficulties with language

**Creutzfeldt-Jakob disease** is a rare, rapidly fatal brain disorder affecting memory, behavior, and coordination ("mad cow disease")

**Normal pressure hydrocephalus** causes difficulty walking, memory loss, and bladder incontinence and can sometimes be corrected by placing a shunt into the brain to drain fluid

**Huntington's disease** is caused by a defective gene on chromosome 4 which causes involuntary movements, problems with thinking, and mood changes

**Wernicke-Korsakoff syndrome** is a memory disorder caused by a severe deficiency of thiamine usually caused by alcohol misuse.

#### **CHARACTERISTICS OF DEMENTIA FRIENDLY COMMUNITIES**

- Broad awareness and recognition of the signs of dementia and how to communicate with people with dementia
- People with dementia can go about their daily activities, have a voice and make decisions, and contribute to community life for as long as possible with understanding, respect, and support from their care partners and other community members.
- People with dementia can live safely and be as independent as possible in settings that promote physical, mental, intellectual, emotional, social and spiritual wellness.
- People with dementia-like symptoms can receive an accurate and timely assessment and diagnosis followed by optimal treatment, support, and care
- People with dementia and their families, friends, and care partners have easy access to supportive options, information and resources, such as education on disease process, self-care, and providing care
- Resources and support are available and accessible to all people regardless of where they live, their cultural background, or their economic status

\* Alzheimer's Association, <http://www.alz.org/dementia/types-of-dementia.asp>

#### **DISCUSS WHAT BEING A DEMENTIA FRIENDLY COMMUNITY MEANS FOR YOUR COMMUNITY**

- Share the key elements of a dementia friendly community.
- What items may address the greatest needs in our community?
- What items do we already have in place?
- Discuss the value of completing the Community Engagement Tool.
- Which questions can be addressed at this meeting?
- Which questions need further investigation?
- Who can follow up on those? Make assignments and discuss when research should be completed.
- Are there others in the community we need to involve to assess how we are currently doing as a community? Who are they and who would be the best person to contact them?

#### **NEXT STEPS**

- Document all assignments for follow up.
- Team Operations:
  - What method works best for on-going team communication (email, calls)
  - What roles do we need have in place to operate as a team and what organizations/people can take on those roles? (e.g., organizer, facilitator, note taker, time keeper)



- Can we set a standing meeting time? Perhaps once per month?
  - Expectations for participation? (e.g., hours per month/attendance)
- What communication do we need to get out to our organizations/community regarding this initiative? Who will do that?

