Creating Dementia-Friendly Communities in Montana

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33rd Montana Gerontology Society Conference

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Overview

- Alzheimer’s disease – a Public Health Crisis
- Dementia-friendly community – definition and key components
- Innovative initiatives from other states in the US and other countries
- Final thoughts
Why a Alzheimer’s Disease a Public Health Crisis?
The Disease Burden is Large

Across the Nation…

• More than 5 million Americans are living with Alzheimer’s disease, including an estimated 200,000 individuals under age 65 with younger-onset Alzheimer’s.

• This number is set to reach as many as 16 million by 2050.
People and Families are Unaware

• **Underdiagnosed**
  – Among individuals *with* Alzheimer’s disease, only about half have ever been diagnosed.

• **Not informed**
  – Less than half of seniors *diagnosed with* Alzheimer’s disease or their caregivers are aware of the diagnosis
Societal Burden is Great

- Most expensive disease in America
- The national cost for caring for those with Alzheimer’s disease in America will be about $226 billion in 2015
- Two thirds of this will be paid by Medicare and Medicaid
- Unchecked, by 2050 Alzheimer’s disease will cost over $1.1 trillion (in 2015 dollars)

*Data are in 2014 dollars.

Created from data from the application of The Lewin Model to data from the Medicare Current Beneficiary Survey for 2008. "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.
Alzheimer’s is a Deadly Disease

- 6th leading cause of death in the US
- Of the top 10 causes of death, it’s the only one that cannot be prevented, cured, or even delayed
Alzheimer’s disease has a devastating effect not just on those with the disease but also on their caregivers. In the US in 2014:

- 15.7 million family and friends provided
- 17.9 billion hours of unpaid care valued at
- $217.7 billion
Montana Alzheimer’s Statistics

• Currently 11% of our seniors have Alzheimer’s disease - 19,000 individuals. By 2025 this number will reach 27,000
• 6th leading cause of death in Montana
• Caregiver burden
  – 48,000 caregivers provided
  – 55 million hours of unpaid care valued at
  – $668 million in 2014
Our challenge as Montanans is to figure out how to provide the necessary care and services to the increasing number of individuals with Alzheimer’s disease and their caregivers no matter where they live until there is a cure or effective disease modifying treatment for individuals with the disease.
Potential Solutions

• Develop a Montana State Plan for Alzheimer’s disease and other related dementias to:
  – Help inform our state government and citizens on critical dementia issues across the state.
  – Provide a set of recommendations on how to improve and support Alzheimer’s disease care and services
  – Create a roadmap on how to become a dementia-capable state

• Engage Montana communities to become dementia friendly by:
  – Recognizing the need to act and change in order to support people with dementia
  – Build supportive, dementia-friendly environments that takes into account the views and opinions of people with dementia and their caregivers
Concept of dementia-friendly is an emerging one and there is not yet an extensive body of literature.

2013 Report provides:
- Evidence on dementia-friendly communities from the prospective of people affected by dementia and their caregivers
- Explores barriers that people face in their communities, how they would like to be engaged with their local area, and the support they need to do so
- Provides a definition of a dementia-friendly community
- Lays out 10 areas of focus for communities working to become dementia-friendly
Why the need for Dementia-Friendly Communities

Many patients with dementia:

• Do not feel supported and a part of their local community.

• Are not able to take part in activities that they enjoyed before they developed the condition obtain due to lack of confidence, worry, and fear.

• Feel that they can’t or don’t know how to contribute of their local community. There is an overriding sense of low expectations and low self-esteem
Common Individual Barriers to Community Involvement

- A lack of confidence (69%)
- Being worried about being confused (68%)
- Being worried about being lost (60%)
- Mobility issues (59%) and physical health issues (59%)
- Not wanting to be a burden to others (44%)
- Lack of adequate transport (33%)
Common Community Barriers for Individual with Alzheimer’s

- Stigma or lack of understanding about dementia from the general public (65%)
- A lack of formal and informal support from others to carry out the activities they want to do (57%)
- A lack of appropriate activities for people with dementia to do (53%)
Excerpt from Alzheimer’s Association Caregiver Tips and Tools to help illustrate community barriers
A dementia-friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing that they can contribute and participate in activities that are meaningful to them.
10 Key Attributes of a Dementia-friendly Community

- Ensure an early diagnosis and post-diagnostic support.
  - Have health and social care services that are integrated and delivering person-centered care
- Provide practical support to enable engagement in community life
- Provide community-based solutions.
  - Support people with dementia in whatever care setting they live
- Have consistent and reliable travel options
- Have easy-to-navigate environments
- Create respectful and responsive businesses and services
  - by promote awareness of dementia in all shops, businesses, and services.
10 Key Attributes of a Dementia-friendly Community

- Involve people with dementia
  - Shape communities around the needs and aspirations of people living with dementia and the views of their caregivers
- Challenge stigma and build understanding
  - Increase public awareness
- Offer accessible community activities
  - Organized activities that are specific to individual with dementia
  - Include in existing community leisure and entertainment activities
- Ensure people with the disease acknowledge their potential to make a positive contribution to their communities
Conceptual View of Dementia-friendly Community

Designed or all stages of Alzheimer’s disease and other related dementia
Becoming an informed, safe, and respectful community for people with dementia involves:

– Raising awareness and transforming attitudes
– Having supportive options that foster quality of life
– Supporting caregivers and families
– Including diverse populations
– Promoting meaningful participation in community life
It seems daunting but even small changes can help communities become dementia-friendly
Examples of community efforts

“Middleton businesses are leading the way to a dementia friendly Dane County.”

- Business dementia-friendly training program in partnership with Alzheimer’s and Dementia Alliance of WI
- Businesses included Walgreens, State Bank of Cross Plans, ACE Hardware, Fitzgerald’s Restaurant, and Willy Street Co-op
- Goal: 50% or more of employees complete the training
Intergenerational Schools in the UK
Creating a “dementia-friendly generation”

Dementia4Schools Project

• Educating children and young people about dementia is an essential aspect of creating dementia-friendly communities.

• Aims
  – sessions would educate children and young people about dementia, remove stigma and provide the opportunity for interaction with people with dementia.
  – give schools the chance to reach outwards and really embed the school as a part of the community.
  – students to gain real insight into not only dementia but also wider issues such as learning about compassion, understanding of older people, and illness.

• Project activities were developed by schools themselves with teachers and students often coming together to work out what will work best in their own school and community.
  – School choir visits to local care homes
  – Homework research into dementia
  – Dementia-focused worksheets
  – Interviewing older family members to create life story book.
Drivers for Change: dementia-friendly bus transport in Northumberland

• The County has established the Northumberland Dementia Forums which draw together people with dementia, their carers and voluntary organizations.

• These groups raised issues about using local buses, especially for people in rural areas once the individual or their carer had to give up driving, including concerns around bus staff responding to people with dementia and recognizing mobility or sensory issues such as hearing loss.

• Dementia awareness training package for local bus drivers for inclusion in the Certificate of Professional Competency. Done in partnership with the existing providers of driver training to develop an enhanced package that focuses on awareness and practical measures to support passengers.
UK Early Diagnosis Pilot Projects

• Goal to increase diagnosis rates in two communities in England

• Intervention:
  – Targeting media outlets to highlight the issue of under-diagnosis
  – Engaging local stakeholders
  – Holding dementia awareness events throughout the community
  – Distributing *Worried about your memory?* Materials
  – Engaging local PCPs and health providers
UK Early Diagnosis Pilot Projects

• Results
  – Improvements in the uptake of information on early diagnosis and the number of people acting on concerns about dementia
  – Increase in memory clinic referrals
  – 60% of PCP practices in the communities reported an increase in the size of their dementia registries over the period of the pilot project

• Conclusions
  – Combined approach, incorporating increased public awareness, media activity, health professional engagement, and stakeholder engagement, can improve awareness and diagnosis of dementia
Think Again Program

Post-diagnostic support program

- Eight week program of therapeutic group sessions
- Two staff members
- Each session focuses on particular aspect with part of each session split into two groups: people with dementia and caregivers
- Explore strategies to cope with communication difficulties, relationship changes, and memory
- Consider ways to do the things have always done
Lifeside Farms: Creating Person-Centered Support through Unlikely Partnerships

• Successful Montana pilot in Flathead Valley based on proven model from Europe sponsored by A Plus Health Care partnering with Area IX Area on Aging
• Day program for seniors and people with disability in which they”
  – Share life with the people living on and running the farm
  – Help with chores, prepare and share lunch and take part in social moments of farm life
• Offered at 8 different farms in Flathead and Lake County and is expanding. Win-win for participants and farmers
• Proven model in many other countries and have been shown to reduce health-related costs, improve quality of life and increase community integration for the participants.
Hegeweyk Dementia Village
Alternative to Nursing Home Facilities

• Built in the Netherlands in 1992 replacing existing nursing home
• Specially designed village with 23 houses for 152 dementia-suffering seniors
• Residents manage their own households together with a constant team of staff members. Daily groceries are obtained in the Hogeweyk supermarket
• Village amenities
  – Streets, squares, gardens and a park where the residents can safely roam free
  – A selection of facilities, like a restaurant, a bar and a theatre.
  – Supermarket, hair salon, post office
Hogeweyk, a Dutch Dementia Village
Arial View
Hogeweyk Entrance
The Village of Hogeweyk
Health Care, Education and Research
What are the next steps?

Designed or all stages of Alzheimer’s disease and other related dementia
Potential Next Steps

• Have a Montana State Plan for Alzheimer’s disease and other related dementias that provides the roadmap on how to become a dementia-capable state

• Engage Montana communities to become dementia friendly by building supportive, dementia-friendly environments that takes into account the views and opinions of people with dementia and their caregivers

• Facilitate collaboration among government agencies, the private sector, and most importantly individuals with dementia and their caregivers

• Make the economic case for creating dementia-friendly communities

• Measure success – select and track outcomes
Toolkits for Creating Dementia-friendly Communities

- Alzheimer’s Society – United Kingdom
  www.innovationsindementia.org.uk/projects_communities

- Minnesota ACT on Alzheimer’s initiative
  www.actonalz.org/dementia-friendly

- Alzheimer’s Disease International
  www.facebook.com/pages/Dementia-Friendly-Communities-CIC
89,000 Minnesotans age 65+ live with Alzheimer’s disease and the number is growing. Communities are taking action.

This site provides a toolkit and resources to guide communities in becoming dementia friendly, practice tools to assist professionals in identifying and managing the disease and an economic model of dementia intervention with projected cost savings.

ACT on Alzheimer’s is a volunteer-driven collaboration bringing Minnesotans together to create supportive environments for everyone touched by Alzheimer's disease and prepare Minnesota for its impacts.

At a Glance
Preparing Minnesota Communities (brochure)
The work and passion of ACTing (videos)
Thank you!
Questions?