Survey of Dementia Friends Minnesota Champions

Summary Report

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Background

ACT on Alzheimer’s conducted a survey of Dementia Friends Champions (registered through ACT) in June, 2017. Of the 184 registered Champions, 74 participated in the survey, a 40.2% response rate. Note: Champions who had delivered an Information Session were the intended participants.

The purpose of the brief, general survey was to identify common questions asked by participants in a Dementia Friends Information Session. Additionally, we wanted to gauge a Champion’s knowledge and distribution of community resources and services when offering Dementia Friends sessions across community sectors. The community sectors are:

- Business Sector
- Civic Organization
- Community Members (not affiliated with a sector)
- Education
- Faith Community
- Government
- Library
- Medical/Health Care
- Senior Housing
- Social Service Organization
- Youth/Teens
- Other

A more comprehensive Dementia Friends Champions survey will be sent Fall 2017 to collect more qualitative and quantitative data for assessing Dementia Friends Minnesota. The next survey will be for all Champions versus only those who have delivered an Information Session.

All registered Dementia Friend Champions were sent the following message and invitation to participate in the survey on June 15, 2017:

You are receiving this email because you are registered as a Dementia Friends Champion.

Your input is needed! We are seeking your input on the common themes or questions that are heard in a Dementia Friends Information Session and the types of resources provided. Your responses will help improve the Dementia Friends MN program. The survey will take approximately 5 minutes to complete. Please complete by Monday, June 26th. Thank you in advance for completing the survey.

Survey link: [https://www.surveymonkey.com/r/DCG5XJP](https://www.surveymonkey.com/r/DCG5XJP)

The survey closed on June 27, 2017. Of the 74 respondents, on average 46 completed all survey questions.
Survey Results

Question 1:

Have you facilitated a Dementia Friends Information Session in the past year? If yes, please continue. If no, please exit this survey.
Answered: 64  Skipped: 10

![Bar Chart]

<table>
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<th>Responses</th>
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<tr>
<td>Yes</td>
<td>71.88%</td>
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<tr>
<td>No</td>
<td>28.13%</td>
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<tr>
<td>Total</td>
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Question 2:

It’s important to record and learn the common themes or questions that Dementia Friends participants have. Please review the following table and check the boxes for the themes/questions you have heard for each sector listed. The table is organized in alphabetical order by community sector.
Answered: 49  Skipped: 25

Results are listed by sector in the order listed in alphabetical order. There are 11 sectors:

- Business Sector
- Civic Organization
- Community Members (not affiliated with a sector)
- Education
- Faith Community
- Government
- Library
- Medical/Health Care
- Senior Housing
- Social Service Organization
- Youth/Teens
- Other
The current Dementia Friends curriculum is comprehensive and touches on key elements of being dementia friendly. Since rollout of the program in Minnesota, some common themes have been identified by Dementia Champions, ACT on Alzheimer’s action team leaders, and ACT staff to help inform the survey:

- Types of dementia
- Dementia facts or statistics
- Communication tips
- How to create a dementia friendly environment
- How to provide hands-on care
- Caregiver support
- Services for family caregivers
- Services for people with dementia
- Other

The table below depicts responses given for each above theme across all 11 sectors. Of the 8 identified themes, “communication tips” and “types of dementia” had the most responses. “How to provide hands-on care” had the fewest responses.

See Appendix A for Common Themes by Sector.
Question 3:

What other common themes or questions came up? Please specify the sector.
Answered: 17    Skipped: 57

Response number 1 (R1)- Community members: How do I have conversations with family members or loved ones who have symptoms or "warning signs" of dementia to get a diagnosis when they do not want to go to the doctor for a screening? 
Senior housing: Can I attend a Dementia Friends session twice as a refresher?

R2- No sector identified: Younger onset Alzheimer's, food [nutrition] and how treatments and drugs work.

R3- No sector identified: Help with challenging behaviors.

R4- Community members: Dementia Friend Champions often come with specific questions about their loved ones. They struggle to find answers and help.

R5- No sector identified: There almost always were questions from people who were caregivers or knew a close friend or relative who needed support. I received questions about communication and understanding behaviors of the one living with dementia. I was asked about local resources offering support such as respite care and concerns about vulnerability of ones living alone with dementia.

R6- No sector identified: We have transportation available within our organization, so questions about how to listen and serve those with dementia came up: repeating questions, if they notice a problem who to contact, how to be patient, etc.

R7- Community members: I wish I knew this information earlier!

R8- No specific sector identified (response was “All groups”): What are specific local resources available - support groups, adult day programs, social worker contacts - name, phone, address etc.

R9- No sector identified: Sharing information from personal experiences with people they know with dementia.

R10- No sector identified: Most people seem to really appreciate the communication portion of the presentation as well as the activity when they are writing out the steps it takes to complete a task.

R11- No sector identified: Dementia Friends questioned the first key message-- with so many people having or expected to have dementia, how come it is not a "normal" part of aging? They also wondered if you could say "natural" part of aging rather than "normal".

R12- Community members and faith community: The attendees are typically older adults or staff that may encounter or support those with memory issues. Some people have very
specific questions about types of dementia, symptoms, diagnosis, prognosis, etc. mainly because they or someone they love are dealing with this currently. I usually try to briefly address the question, but then refer to provider or ask if we could talk further after the Dementia Friend session.

R13- No sector identified: Personal experience with person with dementia was common in each sector.

R14- No sector identified: General understanding and care for people with dementia.

R15- Community members: Most common question is how to cope with personality changes and the abnormal behavior changes associated with cognitive decline.

R16- Senior housing and senior center: How is dementia the same as or different from senility?

R17- Senior housing: Requesting additional communication tips and suggestions was common.

Of the 17 responses listed as “other,” communication, dementia education and supporting family caregiver emerged as common themes from several different sectors.

**Question 4:**

Did you provide a compiled list of community resources at the Dementia Friend Session(s) you facilitated? Please fill in the appropriate answer below and provide resource examples, if possible.

Answered: 47 Skipped: 27

<table>
<thead>
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<th>Answer Choices</th>
<th>Responses</th>
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<tbody>
<tr>
<td>Yes, my community/organization has a list compiled resources.</td>
<td>80.85% 38</td>
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<tr>
<td>No, my community/organization does not have a list compiled resources.</td>
<td>14.89% 7</td>
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<tr>
<td>I'm not aware of a resource list.</td>
<td>4.26% 2</td>
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<td>Total</td>
<td>47</td>
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Responses below are summarized by category and indicate how many Dementia Friend Champions listed a specific resource. A number listed next to the resource indicates how many times that specific resource was mentioned by respondents.

**Statewide resources:**

- ACT on Alzheimer’s- After a Diagnosis handout
- ACT on Alzheimer’s- Dementia Friendly Faith Community handout
- Alzheimer’s Association (12)
- Alzheimer’s Association- 10 Easy ways to help an Alzheimer’s Family handout
- Alzheimer’s Association- Behavior and caregiver support brochures
- Alzheimer’s Association- Caregiver Support group information
- Alzheimer’s Association- Communication tips brochure (2)
- Alzheimer’s Association- Helpline card
- Alzheimer’s Association- Knowing the 10 Signs brochure (2)
- Caregiver's Guide to Wandering
- Minnesotahelp.info (2)
- Senior Linkage Line (9)

**Local resources, organizations or programs:**

- Cherrywood Advanced Living
- Dementia and Alzheimer's community resource guide
- Elder Network
- Friday and Friends
- HealthEast’s Memory Loss Clinic at Bethesda
- Health Partners Center for Memory and Aging
- Mankato/North Mankato resources guide for Dementia Friend Champions
- Paynesville Area flyers
- Rochester ACT on Alzheimer's Community Booklet
- Rose Center
- Southeastern Minnesota Area Agency on Aging (SEMAAA)
- SPN ACT Bookmark or brochure (4)
- Teal’s Market Volunteers
- Wilder Caregiver Services
- Winona Health

**General resources:**

- Caregiver support groups (4)
- Community contacts
- Community resources for families
- Education
- Housing
- Local and regional printed resource guides/brochures
- Local Memory Café info (2)
- Nutritional support
- Organization classes and resources
- REACH (Resources for Enhancing Alzheimer’s Caregivers Health) brochures
- Respite options
Additional comments:

- We have a comprehensive list of community resources handout to give at DF sessions. I also provide a copy of our WCDAN (West Central Dementia Awareness Network) brochure, the bookmark of 10 signs with the Alzheimer’s toll free number on the back, and information about our Memory Café.

- SPN ACT sends out a bimonthly newsletter that lists local DF sessions and trainings, dementia specific resources, events, research updates, etc. It would be great if our Champions could bring an email sign up for DFs who want to add their email to list.

- Dementia and Alzheimer’s community resource guide. The brochure lists local (surrounding counties) and regional resources (i.e. Alzheimer’s Association, Senior LinkAge Line, etc.).

- The resource list is one of providers serving our county and the common contact phone numbers such as the Alzheimer’s Association, the Senior Linkage line and the MN INFO website along with a couple other websites. We also encourage veterans to be in contact with their local VA office and always recommend primary care as the entry point for access to services.

- We are looking at creating our own local program contacts resource guide.

- We verbally suggest the resources available in our community. We also talk about the ones listed in the handbook.

- So far, we have provided this education to those that are familiar with our services so felt there was not a need for any further information at this time.

- Printed resource card for local/state/national resources.

- I provide information from the services that my organization has.

- Senior LinkAge Line is a good fit for us since it is housed in our agency. We encourage people to call Senior Linkage Line to get whatever resources they need for whatever the situation brings anywhere from services to caregiver supports.

- We are developing our phase 4 plan which includes creating a resource guide, but it has not yet been created.

- We have a list but not complete.

A limitation to the findings for question 4 is that the survey did not ask participants to specify the sector for resources offered. Future research could ask for sector-specific resources made available during Dementia Friend sessions.
Question 5:

What resources and organizations would you suggest to individuals who may show signs of dementia?
Answered: 38 Skipped: 36

Responses are summarized by category and indicate how many Dementia Friend Champions listed that specific resource or organization for individuals who may show signs of dementia. A number (e.g. “4”) listed next to the resource or organization indicates how many times that specific resource or organization was mentioned by respondents.

**Statewide resources:**
ACT on Alzheimer's (5)
Alzheimer's Association (23)
Senior Linkage Line (7)

**Medical resources:**
CentraCare Health System
Home health care
Mayo Clinic HABIT program
Memory Care Clinics (2)
Neurologist (5)
Start with primary care physician (15)
Winona Health

**Local non-medical resources:**
Becker Community Center
Becker Senior Center (ACT has resources available at the senior center)
Elder Network
Faith-in-Action (Act has resources available at FIA)
Family Pathways (2)
Consumer Directions
Friday and Friends in the Paynesville Area
Good Samaritan Society Community Centers (Senior Center)
Isanti County Resource Guide
Senior Advocacy
Southeastern Minnesota Area Agency on Aging (SEMAAA)
Wilder caregiver support services (2)

**General resources:**
Books to read about dementia
Care coordination services (2)
Family [talk to]
Faith community
Local memory cafes (3)
"Meet ups"
Memory loss information sessions
Memory screen at social service agency
Support groups (4)

Additional comments:
- If in St. Paul area, go directly to dementia specific medical providers listed in SPN ACT resources for help if their doctor is not helpful with diagnostic and referrals.
- I let them know what our program has to offer them with an in-home visit.
- I first listen to what the person says or what I observe. Based on that, I offer information about where assessments can be completed, facilities with memory loss units, support groups, memory café, Alzheimer's Association, senor day care providers, Area Agency on Aging, home care organizations, assisted living, SNFs, etc. These are all included on the comprehensive list we distribute. I tailor it to fit the needs of the person.

A limitation to the findings for question 5 is that the survey did not ask respondents to identify what organization they were referring to. As a result, some of the comments are very generic.

**Question 6:**

**What resources and organizations would you suggest to family caregivers?**
Answered: 38 Skipped: 36

**Statewide resources:**
ACT on Alzheimer's (6)
Alzheimer’s Association (15)
Alzheimer's Association- Caregiver Support Groups (2)
Alzheimer’s Association- Meeting of the Minds annual conference
Senior Linkage Line (11)

**Local resources for caregivers:**
Becker Community Center
Becker Police Department
Becker Senior Center (Act has resources available at the senior center)
CentraCare Health System
Elder Network
Elder Network in Rochester
Faith-in-Action (Act has resources available at FIA)
Family Pathways- Caregiver Consultants (3)
Friday and Friends
Hopkins Open Circle- Caregiver consultations
Living at Home/Block Nurse Program
Lyngblomsten
Moms meals
REACH providers
Senior Advocacy
Southeastern Minnesota Area Agency on Aging (SEMAAA) (4)
Teal's Market
Walker Methodist
Wilder- Caregiver support services (6)
Wilder- Powerful Tools for Caregivers (2)
Winona Health

**General resources for caregivers:**
Adult day services (2)
Books to read about dementia (2)
Care coordination services (2)
Caregiver services
Caregiver support groups (12)
Dementia support specialist
Faith community (2)
Health care (2)
Home health supports
Memory cafes (3)
Respite (3)
Self care and managing own health and well-being
Senior advocates
Social service agency (3)

**Additional comments:**
- Beyond the Alzheimer’s Association, we need to create a west suburban resource guide.

Depends on the need, if person has already received an Alzheimer's diagnosis, I would suggest local organizations for caregiver coaching and support, support groups, services in community (adult daycare, transportation, medical ID, etc.).
Finding: A significant number of Dementia Friends Information Session participants have questions about communication.

Action: The current Information Session materials contain tips on communication and how to communicate effectively. When training Champions, Master Trainers should stress the importance of the communication section and spend time modeling how to facilitate this part of the Information Session. Additionally, a link to the Alzheimer’s Association could be added to the Session Workbook for those who want to learn more about communication: https://www.alz.org/care/dementia-communication-tips.asp

Finding: Information Session participants have questions about the types of dementia and dementia facts/statistics.

Action: Because Champions are not expected to be experts in dementia or Alzheimer’s disease, Champion trainings must continue to reinforce that participants with questions should be referred to the Alzheimer’s Association 24/7 Helpline (800.272.3900).

Finding: Survey results showed that the majority of Information Session participants are community members not affiliated with a sector. Questions raised are fairly consistent across all themes.

Action: As much as possible, Champions should be aware of additional educational offerings in the community. If offerings do not exist, communities and organizations should determine how they can fill this gap in education.

Finding: Businesses, faith communities, and libraries had questions related to creating a dementia friendly environment.

Action: Champions can refer these sectors to a second training, ACT’s Dementia Friendly @ Work, where they can learn tips for creating a dementia friendly environment in any community setting. The training includes case studies and discussion relevant to the setting.
**Finding:** Youth and teens have questions related to types of dementia, facts and statistics and communication.

**Action:** Review the Dementia Friends Information Session materials to determine possible adaptations for educating youth and teens. An expert or individual trained in dementia may be better suited to deliver a session to youth and teens. It may be possible to work with classroom educators to encourage use of existing educational materials, such as http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp and https://www.alzheimers.org.uk/info/20117/creating_a_dementia-friendly_generation

**Finding:** Champions are knowledgeable about, and are providing information on, local community resources.

**Action:** Champion trainings should continue to stress the importance of understanding local community resources available. If a Champion is unaware, they should connect with the Alzheimer’s Association, local Area Agency on Aging or local ACT on Alzheimer’s community. If resources allow the organization or community could create a guide, flyer or brochure of community resources for people living with dementia and family caregivers.

**Finding:** Champions are knowledgeable about Minnesota’s statewide resources (Alzheimer’s Association MN/ND and the Senior LinkAge Line®) and are referring session participants to these resources.

**Action:** Master Trainers should continue to inform Champions about the Alzheimer’s Association MN/ND and the Senior LinkAge Line®. These resources are also listed in the Session Workbook.

**Additional Takeaways**
Responses on common themes or questions lends insight into additional education -- communication, dementia education and supporting family caregivers -- that could be provided outside of the Information Session.

This survey had a high response rate given that the only incentive was contributing to the improvement of the Dementia Friends Minnesota program. Thank you to all our Dementia Friend Champions who participated in this survey!
Appendix A: Common Themes by Sector

**Business Sector Response**
- Types of dementia: 19%
- Dementia facts or statistics: 11%
- Communication tips: 33%
- How to create a dementia friendly environment: 25%
- How to provide hands-on care: 2%
- Caregiver support: 4%
- Services for people with dementia: 4%
- Services for family caregivers: 2%

**Civic Organization Response**
- Types of dementia: 17%
- Dementia facts or statistics: 20%
- Communication tips: 24%
- How to create a dementia friendly environment: 15%
- How to provide hands-on care: 2%
- Caregiver support: 9%
- Services for family caregivers: 4%
- Services for people with dementia: 9%
Senior Housing Response

How to create a dementia friendly environment 10%

Communication tips 18%

Dementia facts or statistics 13%

Caregiver support 13%

Services for people with dementia 16%

Services for family caregivers 13%

How to provide hands-on care 8%

Social Services Organization Response

How to create a dementia friendly environment 14%

Dementia facts or statistics 13%

Types of dementia 13%

Communication tips 14%

Caregiver support 11%

Services for family caregivers 13%

Services for people with dementia 16%

How to provide hands-on care 6%