Overview

The Alzheimer’s Association Cleveland Area Chapter was founded in 1980 by family caregivers seeking support as they navigated the challenges of caring for a loved one with Alzheimer’s disease. Since that time, our organization has grown to serve nearly 10,000 people annually (unduplicated), providing care and support to people across Northeast Ohio and investing in Alzheimer’s disease research. Twenty-eight full-time and part-time staff members serve the region with support from over 200 volunteers each year.

Currently 220,000 people live with Alzheimer’s disease or a related dementia in the state of Ohio and over 600,000 people – primarily unpaid family members – serve as their caregivers. Alzheimer’s is not a natural part of aging, and there is – as yet – no cure, no way to slow the progression, and no treatment. Alzheimer’s is indiscriminate and affects people of all ages, races, socio-economic statuses, family history, and genders. The majority of people with the disease are 65 years or older, but younger people can also develop Alzheimer’s and caregivers are of all ages. Research has shown that some groups are disproportionately affected by Alzheimer’s including women who are more likely to be caregivers and more likely to develop the disease themselves; people with fewer years of formal education; African Americans and Latinos; and people with other health issues, particularly heart disease and diabetes.

Our close partnerships with local agencies and nonprofits help families facing dementia engage services and support earlier in the disease process. Partners include regional Area Agencies on Aging, senior centers, and similar senior and caregiver-focused organizations.

Background

A community-based needs assessment was conducted in Lake County, OH, on December 5, 2018 by the Alzheimer’s Association Cleveland Area Chapter. This data-driven evaluation will be used to identify needs and service gaps within the community, and classify specific service lines for expanded outreach. The process will also help find prospective community partners and champions.

Methods

Methods used to collect data included focus groups and online surveys.

Participation

Focus groups were conducted with approximately 26 residents from Lake County, OH. Participants divided into five groups, randomly, with two staff members serving as facilitators and recorders. Each group worked on six discussion questions, with 10 minutes allotted for each question. Online surveys were distributed to Lake County, OH residents who were invited but were unable to participate in the focus group; 13 completed surveys were returned.
Key Findings

- Community members view Alzheimer’s and dementia as an issue in their community
- Doctors aren’t aware of Association services to refer patients and families
- Community members are unaware of Association services
- There is a stigma around Alzheimer’s and dementia
- Community members identified needs beyond Association care and support services including respite care, adult day programs and transportation
- The words “Alzheimer’s” and “dementia” are used interchangeably and most people are unaware of the difference
- Very few community members are aware of the warning signs of dementia
- Community members are unaware that the Association is inclusive of providing care and support services for all forms of dementia

Recommendations

Our key recommendations for implementation during fiscal years 2020-2021 (July 1, 2019-June 30, 2021) will include:

- **Educate & Empower:** Educate the public about brain health and cognitive aging, changes that should be discussed with a health professional, and benefits of early detection and diagnosis. In particular, with the expansion of community education programming provided within Lake County, OH.

- **Assure a Competent Workforce:** Foster continuing education to improve primary care professionals’ ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management. In particular, we will engage with providers within the Lake Health hospital system.

- **Mobilize Partnerships:** Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people with dementia and their caregivers. In particular, we will strengthen partnerships with the Lake County General Health District, senior centers, faith-based organizations, corporations, and schools resulting in expanded reach.

- **Continuous Quality Improvement:** Estimate the gap between workforce capacity and anticipated demand for services to support people with dementia and their caregivers on an annual basis. We will continuously conduct community assessments at select intervals to determine the required adjustment for service delivery to ensure we are prepared to meet service demands adequately.
Demographics

Focus Group of Participant

- Caregivers: 13
- Person With Dementia (PWD): 2
- Healthcare professionals: 7
- General Community Members: 4
- Other: 1 (Works in related field)

Gender

- Females: 17
- Males: 6
- Unknown: 3

Race/Ethnicity

- White/Caucasian: 26
- Black/African American: 1

How Did You Hear About our Services?

- Alzheimer's Association: 11
- Healthcare provider: 0
- Community Service Provider: 2
- Advertisement: 9
- Employer or Colleague: 2
- Family or Friend: 4
- Other: 1 (Worked at healthcare facility)

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1 Caregivers: 13; Person With Dementia (PWD): 2; Healthcare professionals: 7; General Community Members: 4; Other: 1 - Works in related field
2 Females: 17; Males: 6; Unknown: 3
3 White/Caucasian: 26; Black African American: 1
4 Alzheimer's Association: 11; Healthcare provider: 0; Community Service Provider: 2; Advertisement: 9; Employer or Colleague: 2; Family or Friend: 4; Other: 1 (Worked at healthcare facility)
Results

Data was collected by recorders from each discussion group. Additional results were collected through an online survey, emailed to participants who were invited but were unable to attend the focus group. Results were emailed and sorted based on common themes and key messages.

Question 1:
In thinking about your knowledge about Alzheimer’s, do you view Alzheimer’s as an issue in your community?
- What are 3 warning signs most people would associate with dementia?

<table>
<thead>
<tr>
<th>Common Themes</th>
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| Alzheimer’s in an issue in your community? | Yes it is an issue  
  Community is empathetic  
  Number of assisted living facilities shows how great of an issue it is |
| What do people call this? | Dementia  
  Cognitive Impairment  
  Memory Loss |
| Warning signs | Forgetfulness  
  Hard time doing everyday activities |

Question 2:
What are other barriers to engaging with the Alzheimer’s Association?
- Do you know of our local services?
- Where do people go for this information?

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| Barriers to engaging? | Stigma with the word “Alzheimer’s”  
  Difficulty finding someone to watch PWD  
  Did not know we were NOT Alzheimer’s specific  
  Website is difficult to utilize  
  Fear and denial of diagnosis |
| Do you know of our local services? | Some knew of our services - SHARE, support groups and dementia care coaching  
  Some did not know of our programs |
| Where do people go to for our information? | News-Herald  
  Internet |
Question 3:

Where do local families go to get diagnosed with Alzheimer’s disease or dementia?

- What’s the closest healthcare system where people go for care?
- Which healthcare providers see the most older adult patients?

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<th>Common Themes</th>
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<tbody>
<tr>
<td>Where do families go to get diagnosed?</td>
</tr>
<tr>
<td>Neurologists</td>
</tr>
<tr>
<td>Primary Physicians</td>
</tr>
<tr>
<td>Geriatric Physicians</td>
</tr>
<tr>
<td>Closest healthcare system?</td>
</tr>
<tr>
<td>Lake Health</td>
</tr>
<tr>
<td>University Hospitals</td>
</tr>
<tr>
<td>Cleveland Clinic</td>
</tr>
<tr>
<td>Which healthcare providers see older adult patients?</td>
</tr>
<tr>
<td>Dr. Shariff</td>
</tr>
<tr>
<td>Dr. Baum</td>
</tr>
<tr>
<td>Dr. Lale</td>
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<tr>
<td>Dr. Angela Brinkman</td>
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<tr>
<td>Dr. Dillon</td>
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Question 4:

What role do local healthcare providers play in connecting dementia patients to the proper community resources?

- How do healthcare providers talk about Alzheimer’s and dementia?
- Do they refer people to the Alzheimer’s Association?
- Which healthcare providers are well-trusted and known in the community? (Specifics)

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<tr>
<td>How do health care providers talk about dementia?</td>
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<tr>
<td>Doctors do not refer to dementia or Alzheimer’s</td>
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<td>Brochures in the doctor’s office</td>
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<tr>
<td>Physicians are hesitant to talk about dementia or use the term</td>
</tr>
<tr>
<td>Do they refer people to the Alzheimer’s Association?</td>
</tr>
<tr>
<td>No referral to Alzheimer’s Association</td>
</tr>
<tr>
<td>One professional participant recommended patients to Alzheimer’s Association</td>
</tr>
<tr>
<td>Well-trusted healthcare providers?</td>
</tr>
<tr>
<td>Dr. Tom Locke</td>
</tr>
<tr>
<td>Dr. Amy Hall</td>
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<tr>
<td>Dr. Labadeva</td>
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<tr>
<td>Dr. Chefsky</td>
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<td>Dr. Baum</td>
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<td>Dr. K</td>
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<tr>
<td>Dr. Mekoda</td>
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<td>Dr. Dillon</td>
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Question 5:

Who are trusted community leaders?

- Where do people spend most of their free time – senior centers, faith communities, major social groups, civic organizations (specifics)?
- How do people get their news & information—library, TV, radio, newspaper, social media?

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| Trusted community leaders? | Government officials  
Lake County Council on Aging |
| Where do people spend their free time? | Restaurants  
Senior Centers  
Churches |
| How do people get their news and information? | News  
Newspaper  
Internet  
Libraries |

Question 6:

What suggestions do you have for how the Alzheimer’s Association can better serve individuals affected by Alzheimer’s disease in this area?

- What measureable change would you like to see in one year in your community?
- Who are additional people we should be hearing from?

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| Suggestions on how we can better serve Lake County | Respite (Volunteer based)  
Develop a list of providers  
Activities for caregivers  
More collaborations |
| Changes you would like to see in one year? | More marketing on services and Helpline  
New/ different education programs  
Marketing that mentions the Association provides services for all form of dementia  
Make website more manageable |
| People we should hear from? | Not sure |
Volunteer Interest

Mandatory Volunteer Interest

Acknowledgments

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Melissa Shelton, Vice President, Fund Development
Sarah Sobel, Public Policy & Outreach Manager
Nancy B. Udelson, President & CEO

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