Exhale Memory Café Collective Survey Results
January 2024
“YOU DON’T HAVE TO REMEMBER EVERYTHING TO KNOW YOU’RE HAVING FUN RIGHT NOW.”
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The Ralph C. Wilson, Jr. Foundation and the Health Foundation for Western & Central New York are launching a new arm of the Exhale Collective, an initiative that focuses on building memory cafés. Memory cafés provide essential support and meet the critical needs of caregivers and their loved ones with Alzheimer’s disease, dementia, or a form of cognitive decline. The cafés are designed to provide social support, connection, health, and well-being to older adult participants and their caregivers in a welcoming environment.

As a part of the discovery phase of this initiative, Exhale partnered with Crowley Webb to perform research among their target audience members within the arts and culture organizations that have expressed interest in participating in their program.
Objectives

Initial discovery sessions were held with 11 WNY arts and cultural organizations to learn about them, their visitors, and any potential experience with programming for this target audience.

Based on information from these discovery sessions, this research was conducted to fulfill the following objectives:

- Identify current target audience volume (i.e., caregivers of a loved one with a form of cognitive decline such as Alzheimer’s disease, dementia, etc.) at participating organizations
- Identify awareness of and interest in memory cafés across participating organizations
- Get a sense of overall preferences for programming from this target audience
- Gain opt-in from interested respondents for the Phase 2 qualitative research in-depth interviews
Methodology

We developed a 10-minute online survey that was distributed via email. Email lists were obtained from the interested and participating organizations below. The survey was distributed between 12/12/23–12/22/23.

Participating organizations included:

• Ashford Hollow/Griffis Sculpture Park
• Artpark
• Botanical Gardens
• Buffalo Museum of Science
• Burchfield Penney Art Center
• Cradle Beach/Pathways for Caregivers
• Frank Lloyd Wright's Graycliff
• Frank Lloyd Wright’s Martin House
• Niagara Arts & Cultural Center (NACC)
• Reg Lenna Center for The Arts
• The Buffalo History Museum
Sample

A combined 162,000 emails were distributed to the 11 participating organization subscriber lists leading to **524 completed surveys** making up the survey sample.

With a 95% confidence level, the sample size of 524 was indicative of the WNY population, with an error rate of ±4.3%.

Screening inclusion criteria consisted of:

- Being a loved one, caregiver, or friend of someone with any form of memory loss or impairment
- Either the loved one or caregiver being a WNY resident
- The loved one being 40 years old or older

Quotas were established (when required) to ensure an equitable distribution and collection of results from each organization’s subscriber list.
SUMMARY OF FINDINGS
SUMMARY OF FINDINGS

TARGET AUDIENCE
• About 12% of organizations’ constituent list is in the target audience (caregiver or friend of a loved one with a form of memory loss)
• The majority of loved ones in the surveyed target audience are 70 years old or older, English speakers, with mobility to visit a memory café program
• About half of caregivers spend time with their loved one more than once a week, and are children or grandchildren of their loved one with memory loss*
• There is a range of diagnoses with a fairly even split among forgetfulness with age, mild cognitive impairment, and moderate forms of cognitive impairment

MEMORY CAFÉ AWARENESS
• A little less than one-third have heard of a memory café before
• Of those, only 6% have previously visited one before, with West Falls Center for the Arts being mentioned by a couple respondents

INTEREST LEVELS
• Just under 40% are extremely interested in visiting a memory café, with the most common expected frequency to be once a month
• Those that are not at all interested (17%) mention general lack of interest or physical limitations such as being in an assisted living facility. Additionally, there are concerns with embarrassment or privacy causing their loved one to not be interested in attending
• 38% of those who have not heard of a memory café reported being extremely interested in potentially attending one

*Relationship may be based on those who are more likely to take a survey
SUMMARY OF FINDINGS

IMPORTANT FACTORS
• The majority of factors rated as extremely important were related to respondents’ loved ones
• Top factors were convenient amenities, a stress-free environment, programming around their loved one’s interests, their loved one not focusing on their memory loss, and a fun environment
  • Those who were extremely interested in visiting a memory café were more likely to rate not focusing on memory loss, a fun environment, a stimulating activity, an inclusive environment, and social opportunities for their loved one as extremely important
  • Additionally, those with a loved one with mild diagnoses were less likely to rate trained staff and specialized amenities as extremely important
• Least important factors often were related to the caregiver, including caregiver social opportunity, rest or reprieve, and support and connections
  • However, those with loved ones with more advanced diagnoses (moderate or severe) were more likely to care about caregiver rest, reprieve, support, and connections

PROGRAM PREFERENCES
• Over half would visit a memory café with other family members followed by a quarter just visiting with their loved one
• A hands-on activity and an event with lively music were activity types more than half of respondents show interest in. Other popular activities were a nature-based or outdoor activity, an event with social opportunities, and quietly listening/watching something
  • A discussion or conversation about a topic and a tour were more likely to be selected by those with forgetfulness with age or mild cognitive impairment
• Music, nature, and art were program themes more than half of respondents showed interest in
  • Music was more likely to be selected by those who have a loved one with moderate or severe cognitive impairment while history, architecture, and education/learning were more likely to be selected by those with loved ones with more mild diagnoses
COMMUNICATION PREFERENCES

- Email was the top communication preference to hear about memory cafés in the future followed by the partner organization’s specific website and social media.
  - Facebook was the most common social media preference.
- Over one-third additionally mentioned the preference to hear about memory cafés on a specific website for various memory cafés in the WNY area.
  - Those who are extremely interested in attending a memory café were more likely to have this as a communication preference than those who were not extremely interested.

CAREGIVER CHALLENGES

- A little over 10% mentioned a caregiver challenge as having time to attend a memory café program and having difficulties with going at certain times of day.

LOVED ONE CHALLENGES

- Over 40% mentioned a challenge their loved one would face visiting a memory café with almost half including a physical mobility limitation such as wheelchair access, trouble walking far distances, or balance. Additional challenges included sensory issues with loud noises or hearing loss, the need for restrooms close by, and mood or agitation issues.

ORGANIZATION ATTENDANCE

- Organization attendance correlated with the response rate from provided email lists as well as the size of email lists from each organization.
- About half visit the listed organizations a few times a year.
- The majority (64%) stated their visit frequency has not changed based on spending time with their loved one, however, one-third mention the frequency has become less.
RECOMMENDATIONS
RECOMMENDATIONS

**Memory Café Awareness**
There are many individuals that are very interested in the idea of memory cafés that have not heard of them before. Spreading the word of what memory cafés are and the purposes they serve is important as the cafés are developed which can increase the programs’ popularity.

**Participant Variation**
It may be beneficial to host different types of memory cafés. These should be based on potential participant needs – especially diagnosis stage and the challenges that go with them. For example, those with milder forms of memory loss may not want to draw attention to their condition and prefer a more autonomous program.

**Program Types**
Similar to the need for variation based on diagnosis stage, memory café programs could benefit from various program types. While some chose more active programs (hands-on activity or lively music), others chose something a little more subdued (nature-based activity or quietly engaging with something).

**Important Factors**
Loved ones’ needs, wants, and interests were very important to caregivers to incorporate into memory café development and should be the main determinant of memory café programming. While caregiver needs should also be taken into account, their loved one being happy and taken care of was the main driver in caregiver interest level and potential attendance.

**Accessibility**
Physical accessibility is a top priority for caregivers. Accommodations for physical handicaps (wheelchairs, bathroom access, seating, safe space for moving around with walkers, etc.) is a large contributor to what would make it possible for caregivers to bring their loved ones to memory cafés. The memory café location being ADA compliant would be ideal for many.

**Crossover**
There is a good amount of crossover in visitation among participating organizations. Developing memory café programming holistically would allow for mutual benefits such as awareness, alternative visitor schedules, and program variety.
CAREGIVER AND LOVED ONE INFORMATION
Target Audience Breakdown

Qualification criteria:
- Being a loved one, caregiver, or friend of someone with any form of memory loss or impairment
- Either the loved one or caregiver being a WNY resident
- The loved one being 40 years old or older

162,000 emails were sent to organizations’ subscribers
3.4% of those who received the email started the survey
80% of those who started the survey finished it
12% of those who took the survey met the qualification criteria

5,540 people started the survey
20% started the survey without finishing

4,423 people finished the survey or disqualified
88% did not meet the survey qualification criteria

524 people were qualified and in the target audience
12% of those who took the survey met the qualification criteria
12% of the overall subscriber list is in the target audience for this program

S: Do you currently spend time with, help with errands or household chores, or assist a loved one or friend with any form of memory impairment or memory loss?
Organization Respondents

The breakdown of respondents generally corresponded with the size of each organization’s list that the survey was sent out to. Due to the large sample size (524 individuals), this sample is representative of the WNY population. There was a good amount of crossover of respondents among the various organizations’ email lists.

Note: The chart shows individual organization completion totals accounting for crossover from lists.
CAREGIVER AND LOVED ONE INFORMATION

Geography

The vast majority of caregivers (99%) and loved ones (96%) live in New York state and in one of the 8 WNY counties. Across both groups, most live in Erie County (72% and 71%, respectively).

CAREGIVER STATE AND COUNTY
n=516 (NY only)

<table>
<thead>
<tr>
<th>County</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Erie</td>
<td>72%</td>
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<tr>
<td>Niagara</td>
<td>12%</td>
</tr>
<tr>
<td>Chautauqua</td>
<td>10%</td>
</tr>
<tr>
<td>Genesee</td>
<td>2%</td>
</tr>
<tr>
<td>Allegany</td>
<td>1%</td>
</tr>
<tr>
<td>Cattaraugus</td>
<td>1%</td>
</tr>
<tr>
<td>Orleans</td>
<td>1%</td>
</tr>
<tr>
<td>Wyoming</td>
<td>1%</td>
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</tbody>
</table>

LOVED ONE STATE AND COUNTY
n=503 (NY only)

<table>
<thead>
<tr>
<th>County</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erie</td>
<td>71%</td>
</tr>
<tr>
<td>Niagara</td>
<td>12%</td>
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<tr>
<td>Chautauqu</td>
<td>9%</td>
</tr>
<tr>
<td>Genesee</td>
<td>2%</td>
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<tr>
<td>Allegany</td>
<td>1%</td>
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<td>Cattaraugus</td>
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<td>Orleans</td>
<td>1%</td>
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<tr>
<td>Genesee</td>
<td>1%</td>
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<tr>
<td>Orleans</td>
<td>1%</td>
</tr>
<tr>
<td>Wyoming</td>
<td>1%</td>
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</tbody>
</table>

Note: 2% were outside of a WNY county
Loved One and Caregiver Summary

**LOVED ONE AGE**
80% of loved ones are 70 years or older*

*Loved ones had to be over 40 years old to qualify for the survey.

**CAREGIVER RELATIONSHIP**
45% of caregivers are the child of their loved one, followed by their grandchild (11%), in-law (10%), significant other (9%), and friend (9%)

**LANGUAGE PREFERENCE**
99% of caregivers and their loved ones speak English as their preferred language

**LOVED ONE DIAGNOSIS**
There is even distribution in loved one diagnosis with increased mild forgetfulness with age (30%), a mild cognitive impairment diagnosis (24%), and a moderate cognitive impairment diagnosis (26%)

**VISIT FREQUENCY**
49% spend time with their loved one more than once a week*

*A few times a week OR daily

**MOBILITY**
79% of caregivers and their loved ones are physically able to attend activities out of the home

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Q: How old is your loved one who has a form of memory impairment or memory loss?
Q: What stage of memory impairment or memory loss does your loved one have?
Q: Are both you and your loved one physically able to attend activities, events, or programs outside of your home(s)?

Q: Which best describes your relationship with your loved one?
Q: On average, how often do you usually spend time with or care for your loved one?
Q: Is English both you and your loved one’s preferred language?
The sample contained a predominant demographic of female respondents, primarily identifying as white, with a college degree or higher education degree.

**GENDER**

n=524

- 79% Female
- 19% Male

**RACE AND ETHNICITY**

n=524

- 91% White
- 3% Black or African American
- 3% Hispanic, Latino, or Spanish
- 1% Asian
- 1% Native American

**EDUCATION**

n=524

- 42% A Higher Education Degree
- 40% A College Degree
- 11% Some College
- 3% Career or Technical Education
- 3% High School or GED
- 0% Less than High School

D: Which gender do you identify with? Please select one.
D: What is your race?
D: Are you of Hispanic, Latino, or Spanish of origin?
D: What is the highest degree or level of school you have completed?
MEMORY CAFÉ AWARENESS AND INTEREST LEVEL
Memory Café Awareness

The majority of those in the target audience (72%) had not previously heard of a memory café. Of those who had, only 6% mentioned previously attending one in the past.

**TOTAL RESPONDENTS**

n=524

- Have not heard of a memory café, 72%
- 28% of respondents have previously heard of a memory café after reading a short description (n=145)
- 6% of those who have heard of a memory café have attended one in the past (n=9)

- West Falls Center for the Arts (2)
- Dale Association Memory Café
- Eden United Methodist Alzheimer Association monthly respite program
- East Aurora Adult Daycare
- A musical memories café (not specified)

Q: Have you heard of a memory café?
Q: You mentioned you have heard of memory cafés. Have you ever attended a memory café as either a participant or with a loved one?
Q: What is the name of the memory café you have previously visited?
Memory Café Interest Level

After reading a short memory café description, 39% of respondents said they were extremely interested in visiting a memory café with their loved one, with the most common anticipated visit frequency being once a month (33%) or a few times a month (25%).

For those who were extremely interested in visiting a memory café, the most common visitation range was once a month, similar to both the suggested and anticipated memory café program set up.
Memory Café Interest Level (Cont.)

Less than one-fifth (17%) reported not being interested in visiting a memory café in the future. Of those with no interest (1 rating), the main reason was a general lack of interest or physical limitations such as being in an assisted living facility.

**INTEREST LEVEL**
n=524

- 39%
- 44%
- 17%

*Those expressing no interest in a memory café (1 rating) did not continue through the survey asking about program preferences.

Some mention that while the program may be good for their loved one, there would be concerns with their loved one not being interested in a program that is highlighting their memory loss.

“My loved one has a fairly full social life and would, I think, be turned off by any acknowledgement of their memory changes, such as through a place that is specifically for ppl with memory loss.”

“I’m 100% certain my mother would not be willing to attend as she is very private and tries to hide that her memory is failing. This would draw attention to it and force her to admit it.”

Q: After reading a memory café description, please rate how interested you are in potentially visiting a memory café with your loved one in the future with 1 being “Not at all interested” to 7 being “Extremely interested.”

Q: You indicated you would not be interested in visiting a memory café with your loved one in the future. Would you please tell us why? Please be specific.
Memory Café Opportunity

While almost three-quarters of respondents had not heard of memory cafés, there is still a large proportion of this group who are interested in attending.

Q: Have you heard of a memory café?
Q: Please rate how interested you are in potentially visiting a memory café with your loved one in the future with 1 being “Not at all interested” to 7 being “Extremely interested.”

<table>
<thead>
<tr>
<th>INTEREST LEVEL</th>
<th>TOTAL RESPONDENTS</th>
<th>INTEREST LEVEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely interested</td>
<td>n=524</td>
<td>Extremely interested</td>
</tr>
<tr>
<td>Neutral</td>
<td>Have not heard of a memory café 72%</td>
<td>Neutral</td>
</tr>
<tr>
<td>Not at all interested</td>
<td></td>
<td>Not at all interested</td>
</tr>
</tbody>
</table>

Those who have not heard of memory cafés before are more likely to be not at all interested in attending a memory café compared to those who have heard of a memory café.*

*Those who have not heard of memory cafés before are more likely to be not at all interested in attending a memory café compared to those who have heard of a memory café.**
MEMORY CAFÉ
PROGRAMMING PREFERENCES
Attendance

More than half reported they would visit a memory café with their loved one along with other family members. One-quarter reported they would visit with just them and their loved one.

VISITORS
n=462

- With my loved one plus family member(s) 55%
- Just with my loved one with a form a memory loss or memory impairment 25%
- With my loved one plus friend(s) 10%
- Unsure 12%

Q: Who do you anticipate you would attend a memory café with? Please select the option(s) that fits best.

*Those who have loved ones with moderate or severe cognitive impairment are more likely to visit with other family members than those with forgetfulness with age.
Program Preferences – Activity Types

There were a mix of interests for potential program types with more than half being interested in a hands-on activity or an event involving lively music. Other popular choices were something in nature, a social event, or quietly listening or watching something.

Q: What type of memory café programming would you and your loved one be most interested in potentially attending? Please select all that apply.

- A hands-on activity: 51%
- An event involving lively music: 50%
- A nature-based/outdoor activity or walk: 47%
- An event allowing for social opportunity: 44%
- Quietly listening to or watching something: 44%
- A tour: 32%
- A discussion or conversation about a topic: 31%
- An activity involving dancing: 10%

* Those who were extremely interested in visiting memory cafés were more likely to choose a hands-on activity or an event for social opportunity as a program type than those with lesser interest levels.

** Those who have loved ones with forgetfulness with age or mild cognitive impairment were more likely to be interested in a topical discussion or conversation compared to those with a moderate diagnosis.

† Those who have loved ones with severe cognitive impairment were less likely to be interested in a tour than those with more mild diagnoses.
Program Preferences – Themes

More than half of respondents selected music, nature, or art as a program theme that would be most interesting to their loved one.

Q: What types of program themes would be most interesting for you and your loved one for a memory café? Please select all that apply.

- Music: 67%
- Nature: 60%
- Art: 55%
- History: 47%
- Performance theater: 40%
- Education or learning: 37%
- Games: 35%
- Cultural focus: 31%
- Science: 29%
- Architecture: 23%
- Dance: 19%

**PROGRAM THEMES**

n=462

*Those who have loved ones with moderate or severe cognitive impairment were more likely to be interested a program involving music than those with more mild diagnoses

**Those who have loved ones with forgetfulness with age or mild cognitive impairment were more likely to be interested in a program involving history, architecture, and education/learning than those with more advanced diagnoses

† Those who have loved ones with severe cognitive impairment were more likely to be interested in a program involving dance than those with lesser diagnosis stages

† † Those who are extremely interested in visiting memory cafés were more likely to choose art, music, and nature as a program theme than those with lesser interest levels
Many suggested similar recommendations of what their loved one may enjoy for a program type or theme.

**Program Preferences – Suggestions**

Q: What type of memory café programming would you and your loved one be most interested in potentially attending?

Q: What types of program themes would be most interesting for you and your loved one for a memory café?

- Cards/board games
- Painting or drawing
- Crafting
- Sports
- Food/cooking
- Gardening or plants
- Sewing/quilting/knitting

**SINGLE MENTIONS**

<table>
<thead>
<tr>
<th>A lecture</th>
<th>Folk music/singer songwriter concert</th>
<th>Memories in the making</th>
<th>Science</th>
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<tbody>
<tr>
<td>Agriculture</td>
<td>Hearing stories of the past</td>
<td>Photography</td>
<td>Sit and fit exercises</td>
</tr>
<tr>
<td>Astronomy/Ships and Navigation</td>
<td>Hospice volunteer</td>
<td>Pottery</td>
<td>Something religious</td>
</tr>
<tr>
<td>Classical or jazz music performance</td>
<td>Language based</td>
<td>Prayer</td>
<td>Snack and coffee</td>
</tr>
<tr>
<td>Films/movies</td>
<td>Music therapy</td>
<td>Reading</td>
<td>Virtual sessions</td>
</tr>
</tbody>
</table>

“I would love to see local elementary schools with young children interacting with the elderly. Any time we have get togethers, the older folks are just so smitten watching the little kids or talking to them. It is heartwarming to see.”

“A social activity that she could do seated like bingo.”

“Offer snacks/food/ beverages.”

“Like Scrabble or Boggle. Older folks love the feeling of ‘winning.’ So maybe game show type atmosphere?”

“Sitting with them, quietly, talking a bit, holding their hand, especially when they cannot speak anymore but can hear and see very well.”

Q: What type of memory café programming would you and your loved one be most interested in potentially attending?

Q: What types of program themes would be most interesting for you and your loved one for a memory café?
Most Important Memory Café Factors

The topmost important factors for memory café programming concentrated on an environment that was comfortable and themes focusing on the loved ones enjoying themselves.

From the list of factors rated as extremely important by more than half of respondents, only one was something caregiver specific.

Q: As the caregiver or person that spends time with your loved one, what would be most important for you to see in any future memory café programming? Please rate each factor on a scale with 1 being "Not at all important" to 7 being "Extremely important."
Least Important Memory Café Factors

The factors least likely to be rated as important for memory café programming were often caregiver focused: the top three including caregiver social opportunities, caregiver rest and reprieve, and caregiver support and connections.

Loved one location in proximity to the memory café was the only loved-one-specific factor that was rated as extremely important by fewer than half of respondents.

Q: As the caregiver or person that spends time with your loved one, what would be most important for you to see in any future memory café programming? Please rate each factor on a scale with 1 being “Not at all important” to 7 being “Extremely important.”
**Factor Significant Differences**

There were some statistically significant differences when rating factor importance among those with loved ones at different diagnosis stages as well as those with different interest levels in potentially attending a memory café. These may be worth considering when developing the memory café programs.

### DIAGNOSIS

<table>
<thead>
<tr>
<th>Forgetfulness with age or mild cognitive impairment</th>
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<tbody>
<tr>
<td>• Less likely to rate having trained staff as a very important memory café factor compared to those with any more advanced stage diagnosis</td>
</tr>
<tr>
<td>• Less likely to rate specialized amenities as a very important memory café factor compared to those with a more advanced stage diagnosis</td>
</tr>
<tr>
<td>• Less likely to rate caregiver support and connections as a very important memory café factor compared to those with any more advanced stage diagnosis</td>
</tr>
<tr>
<td>• Less likely to rate caregiver access to resources as a very important memory café factor compared to those with any more advanced stage diagnosis</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Moderate or severe cognitive impairment</th>
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<tbody>
<tr>
<td>• More likely to rate caregiver rest and reprieve as a very important memory café factor compared to those with less severe diagnoses</td>
</tr>
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</table>

### INTEREST LEVEL

<table>
<thead>
<tr>
<th>Extremely interested in visiting memory cafes</th>
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<tbody>
<tr>
<td>• More likely to rate not focusing on memory loss (for both the loved one and caregiver) as a very important memory café factor than those with lesser interest levels</td>
</tr>
<tr>
<td>• More likely to rate having a fun environment as a very important memory café factor than those with lesser interest levels</td>
</tr>
<tr>
<td>• More likely to rate having a stimulating activity for their loved one as a very important memory café factor than those with lesser interest levels</td>
</tr>
<tr>
<td>• More likely to rate having an inclusive environment as a very important memory café factor than those with lesser interest levels</td>
</tr>
<tr>
<td>• More likely to rate having social opportunities for their loved one as a very important memory café factor than those with lesser interest levels</td>
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Caregiver Attendance Challenges

The challenges caregivers mentioned they would have when attending a memory café program often included struggles with time to attend the program or the time of day the memory café is held.

**CAREGIVER CHALLENGES**  n=52

- **11%** mentioned a caregiver challenge

  - **Having the time to go (14%)**
    - “Finding time to fit this into our schedule.”
    - “Finding time to take advantage of visiting a memory café.”
  
  - **Time of day (9%)**
    - “Timing - mornings can be difficult as are evenings. Afternoon is usually best time of day to leave the house.”
    - “Flexible attendance.”

Additional caregiver challenges included transportation of their loved one, some mobility issues, location of the café, and concerns for watching over their loved one.
Loved One Attendance Challenges

Respondents also highlighted challenges their loved ones would have when attending a memory café program. Top challenges were related to their mobility including wheelchair access, difficulty with stairs, and seating availability. The next most common mentions were related to sensory sensitivities.

**LOVED ONE CHALLENGES n=189**

<table>
<thead>
<tr>
<th>Physical mobility limitations (45%)</th>
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<tbody>
<tr>
<td>“She is not as stable on her feet, close parking and ease of use for disabled would be a priority. In addition, comfortable seating is necessary as well as a space without many obstacles to navigate.”</td>
</tr>
<tr>
<td>“Physical ability — they suffer from physical impairment in addition to cognitive impairment. Needs help walking or would need wheelchair access.”</td>
</tr>
<tr>
<td>“Easy access to areas and activities with places to rest or wheelchair available.”</td>
</tr>
<tr>
<td>“He uses a cane but sometimes likes to bring a walker with a seat because he needs to sit sometimes. So, chairs to rest for a few minutes would be great. Something not involving TOO much walking/stairs.”</td>
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<thead>
<tr>
<th>Sensory challenges (10%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Loud noises, over stimulating environment, large crowds.”</td>
</tr>
<tr>
<td>“Hearing loss, variable volume areas, other items to focus on during a talk/presentation - like a readable brochure, or visual items so my loved one can choose how involved she would like to be, without completely missing out on the café experience.”</td>
</tr>
</tbody>
</table>

*Those who have loved ones with moderate or severe cognitive impairment were more likely to mention a loved one challenge than those who have loved ones with forgetfulness with age.*

**41% mentioned a loved one challenge**

Additional loved one challenges included the need for restrooms close by and some mood or agitation issues.

Q: Are there any challenges your loved one may have that would be helpful to factor in for memory café development?
Q: You mentioned there are challenges your loved one may have that would be helpful to know as memory café programs are being developed. Would you please share what the challenge(s) is/are and anything that would help alleviate them?
Memory Café Communication

Email, the organization’s website, and social media (specifically Facebook) were the main preferences for how respondents would like to hear about future memory cafés.

**COMMUNICATION PREFERENCE**

<table>
<thead>
<tr>
<th>Preference</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email</td>
<td>70</td>
</tr>
<tr>
<td>The organization’s website*</td>
<td>59</td>
</tr>
<tr>
<td>Social media</td>
<td>34</td>
</tr>
<tr>
<td>A specific website for various memory cafés in WNY</td>
<td>31</td>
</tr>
<tr>
<td>Direct mail</td>
<td>25</td>
</tr>
<tr>
<td>Online advertisement</td>
<td>23</td>
</tr>
<tr>
<td>Postings at assisted living facilities, etc.</td>
<td>20</td>
</tr>
<tr>
<td>Word of mouth</td>
<td>20</td>
</tr>
<tr>
<td>Television advertisement</td>
<td>18</td>
</tr>
<tr>
<td>Sponsorship of events or programs in the community</td>
<td>15</td>
</tr>
<tr>
<td>Outdoor advertisement</td>
<td>14</td>
</tr>
<tr>
<td>Radio advertisement</td>
<td>13</td>
</tr>
<tr>
<td>Newspaper advertisement</td>
<td>13</td>
</tr>
<tr>
<td>Podcast or digital radio streaming</td>
<td>3</td>
</tr>
</tbody>
</table>

*The organization shown in the survey was based on the email list that the respondent was on.

*Those who are extremely interested in visiting memory cafés were more likely to choose a collective website for memory café information and email as their communication preference compared to those with lesser interest.

Q: How would you prefer to hear about potential memory cafés and their events in the WNY area? Please select all that apply.

Q: You indicated that you would prefer to hear about potential memory cafés through social media. Which social media platforms would you prefer? Please select all that apply.
Notable Verbatim

Throughout the survey, caregivers provided helpful feedback and opinions that could be useful to keep in mind for the early stages of memory café development.

“Please be ADA accessible! This would include slow walkers, unsteady people, canes and or wheelchair access. This should be included in all areas such as parking, entrances, restrooms, café areas, and events held throughout the year such as holiday/vendor markets.”

“The need for dignity and the sensitivity that folks may not be comfortable discussing their challenges openly but could benefit from learning compensatory strategies.”

“Caregivers need a safe space and a break sometimes too!! Having staff trained that might be able to help when/if needed is a great idea. This community is challenging to understand and take care of at times, and it might be nice for a caretaker to not need to apologize for their loved one’s behavior or needs.”

“Sudden change of emotion and mood can create cause for a last-minute change of plans. I feel if there was a different cancelation policy for any prepaid services, I would feel more comfortable signing up.”

“Some individuals might not love music or loud noises! Another option to keep things ‘safe’ might be to have maybe one set craft or activity that we know for sure will be there every time we go might be nice. Options and choices are hard sometimes, and consistency can be more comfortable. Thank you for even considering this idea to be implemented in our community.”

“My mother is hard of hearing and has limited [sight]. Having a presence that isn’t necessarily loud but clear to hear and presentation that is easy to see or able to get close to makes it easier for her to enjoy and participate in mentally.”

“Would be nice to be able to leave my loved one for a little bit if he was around people that were caregivers and didn’t mind keeping an eye on him for a little bit if I needed to go to the bathroom or take a phone call.”

“Scheduling could be a challenge, so different times and days would be helpful.”

“[My loved one] has a lot of nausea and bathroom issues so close accessible bathrooms are critical.”

“As a respite provider for several years, I find that guests respond best to extremely quiet spaces while we are painting or eating. The calm slow-paced discussion of artwork allows one guest at a time to speak. I feel that the loud socializing time at respite would be better spent with singing and dancing, since we have increasingly ‘non-verbal’ guests who seem flustered at socializing.”
ORGANIZATION
VISITATION AND
PREFERENCES
Organization Attendance

Visitation frequency for a particular organization corresponds with the number of recipients on the organization's email distribution list, with the Botanical Gardens and The Museum of Science being the most commonly attended.

Note: 3% report not visiting any of the listed organizations in the last 2 years

Q: Have you visited any of the following locations in the last 2 years? Please select all that apply.

Botanical Gardens
Buffalo Museum of Science
The Buffalo History Museum
Burchfield Penney Art Center
Artpark & Company
Frank Lloyd Wright's Martin House
Griffis Sculpture Park
Frank Lloyd Wright's Graycliff
Niagara Arts and Cultural Center (NACC)
Reg Lenna Center for The Arts
Pathways for Caregivers/Cradle Beach
Hispanic Heritage Council of WNY

Note: 3% report not visiting any of the listed organizations in the last 2 years
Organization Attendance

When asked about attendance frequency, half of respondents reported that they attend one of the locations a few times a year. One-third also mentioned that their visits have become more infrequent due to spending time with their loved one with memory loss.

Q: To the best of your recollection, how often have you visited any WNY arts and cultural organization or event in the last 2 years?
Q: Has spending time with or caring for your loved one or friend with memory impairment or memory loss changed the frequency in which you have visited WNY arts and cultural organizations or events overall?
NEXT STEPS
Qualitative Research (In-Depth Interviews)

Phase 2 of research for the memory cafes will include one-on-one in-depth interviews with survey respondents who opted in to participate in some follow-up questions. Based off findings from these survey results, we will develop a questionnaire guide that will provide more detailed information that is organization-specific and gives us caregiver perspectives.

The main objectives of the qualitative research are to:

- Obtain firsthand perspectives from potential memory café visitors about their experiences as caregivers of loved ones with memory loss
- Identify challenges and listen to suggestions from the target audience that would make it easier or make them more likely to visit a memory café at the specific organization
- Determine organization-specific needs or considerations that should be factored in for potential memory café development at each of the different locations
- Use findings from both the survey and interview research to guide program development and suggestions
THANK YOU.