

Exhale Memory Café Collective Survey Results January 2024



"YOU DON'T HAVE TO REMEMBER EVERYTHING TO KNOW YOU'RE HAVING FUN RIGHT NOW."

TABLE OF CONTENTS

Background	4
Objectives	5
Methodology	6
Sample	7
Summary of Findings	8–11
Recommendations	12–13
Appendix: Key Findings	14–40
Caregiver and Loved One Information	15–20
Memory Café Awareness and Interest Level	21–25
Memory Café Programming Preferences	26–37
Organization Visitation and Preferences	38–40
Next Steps	41–42







Background

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



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



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 $\pm 4.3\%$.

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



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







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

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

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

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



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 cafes 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.

APPENDIX:

KEY FINDINGS

CAREGIVER AND LOVED ONE INFORMATION

Target Audience Breakdown



Qualification criteria:

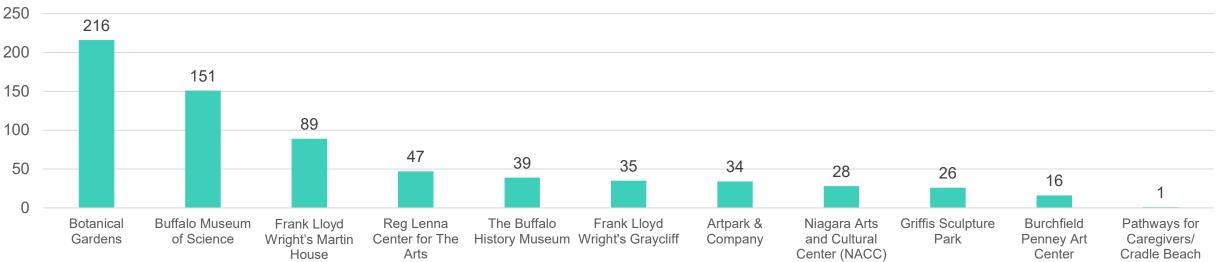
- Being a loved one, caregiver, or friend of someone with any form of memory loss or impairment
- Either the loved one or caregiver being a WNY resident
- The loved one being 40 years old or older





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.



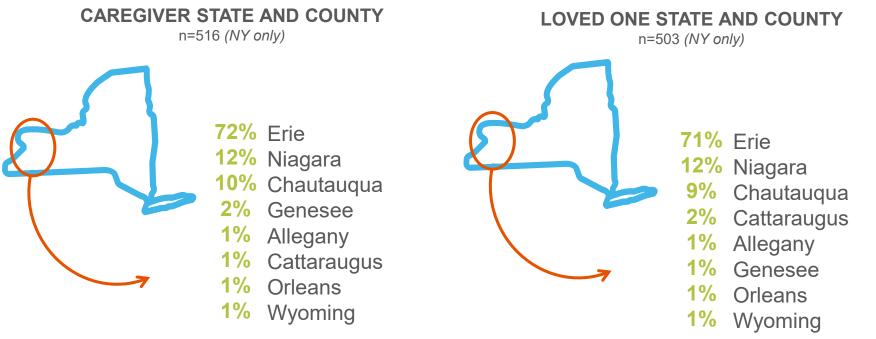
SURVEY COMPLETES n=524

Note: The chart shows individual organization completion totals accounting for crossover from lists.



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).



S: What state does your loved one or friend with any form of memory impairment or memory loss live in? S: What county does your loved one or friend with any form of memory impairment or memory loss live in?



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.

*Those who have loved ones with forgetfulness

with age are more likely

to spend time with their

*Those who have loved

ones with moderate and

likely to spend time with

monthly or yearly basis

loved ones at least

severe cognitive

impairment are more

their loved one on a

weekly

EN.

VISIT FREQUENCY*

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

*A few times a week OR daily



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%)



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%)



LANGUAGE PREFERENCE

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



MOBILITY**

79% of caregivers and their loved ones are physically able to attend activities out of the home **Those who have loved ones with forgetfulness with age or mild cognitive impairment are more likely to be physically able to attend activities outside the home than those with than those with more advanced diagnoses

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?



42%

40%

40%

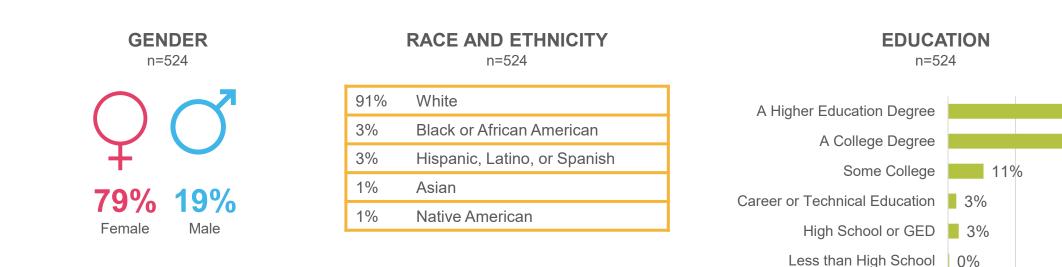
60%

0%

20%

Respondent Demographics

The sample contained a predominant demographic of female respondents, primarily identifying as white, with a college degree or higher education degree.

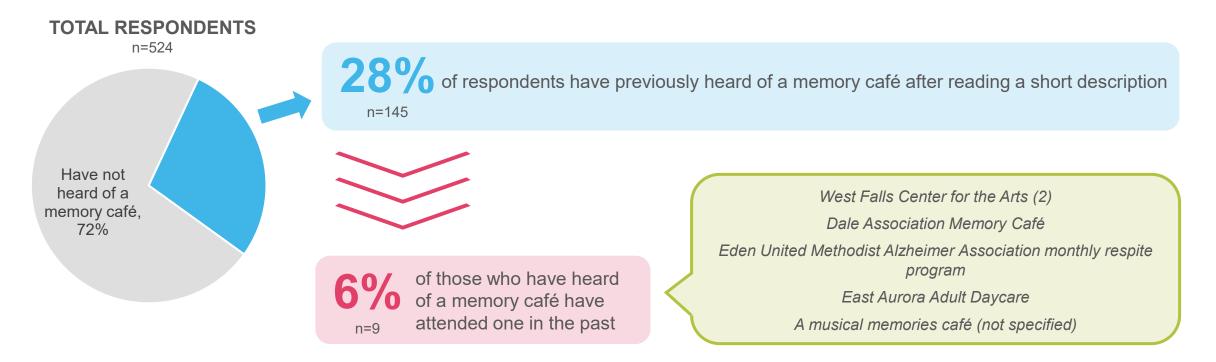


MEMORY CAFÉ AWARENESS AND INTEREST LEVEL



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.



Q: Have you heard of a memory café?

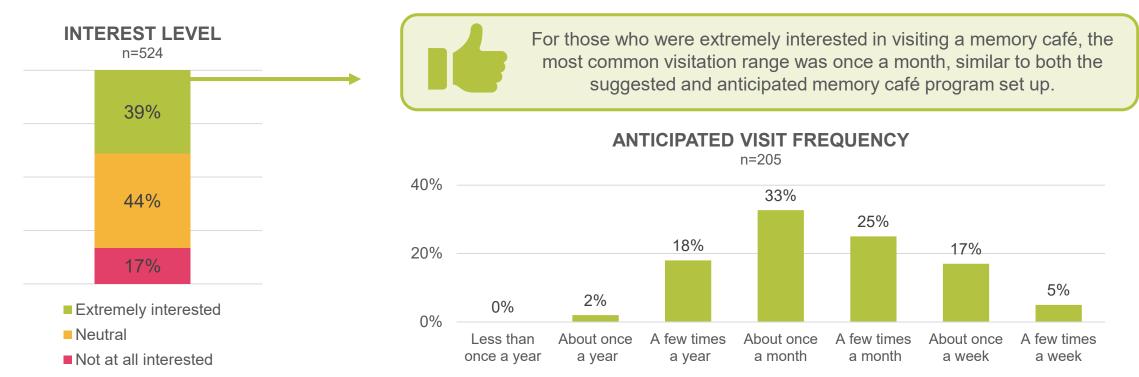
Q: You mentioned you have heard of memory cafés. Have you ever attended a memory café as either a participant or with a loved one?

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%).



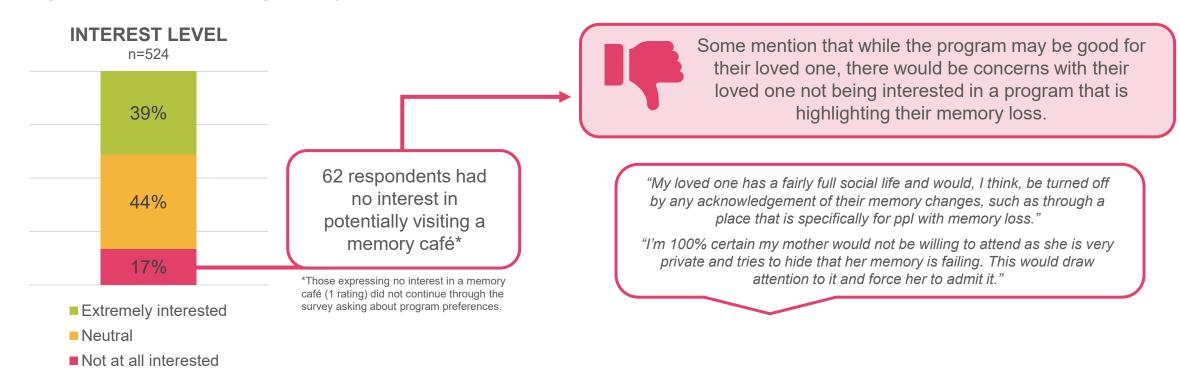
Q: Please rate how interested you are in potentially visiting a memory café with your loved one in the future with 1 being "Not at all interested" to 7 being "Extremely interested."

Q: You indicated you are interested in visiting a memory café with your loved one in the future. How often do you think you and your loved one who has a form of memory loss would like to participate in a program like this? 23



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.

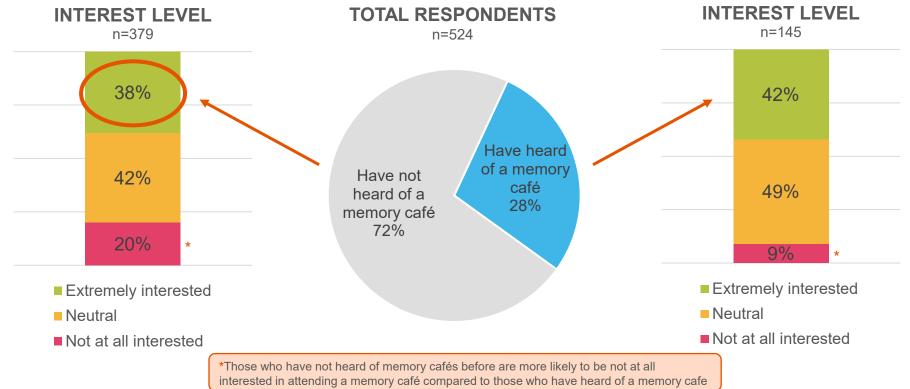


Q: After reading a memory café description, please rate how interested you are in potentially visiting a memory café with your loved one in the future with 1 being "Not at all interested" to 7 being "Extremely interested." Q: You indicated you would not be interested in visiting a memory café with your 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?

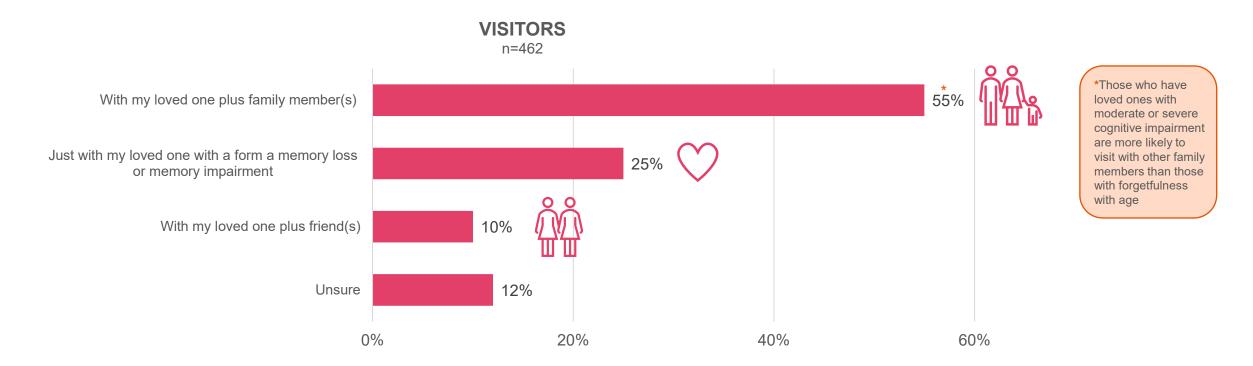
Q: Please rate how interested you are in potentially visiting a memory café with your loved one in the future with 1 being "Not at all interested" to 7 being "Extremely interested."

MEMORY CAFÉ PROGRAMMING PREFERENCES



Attendance

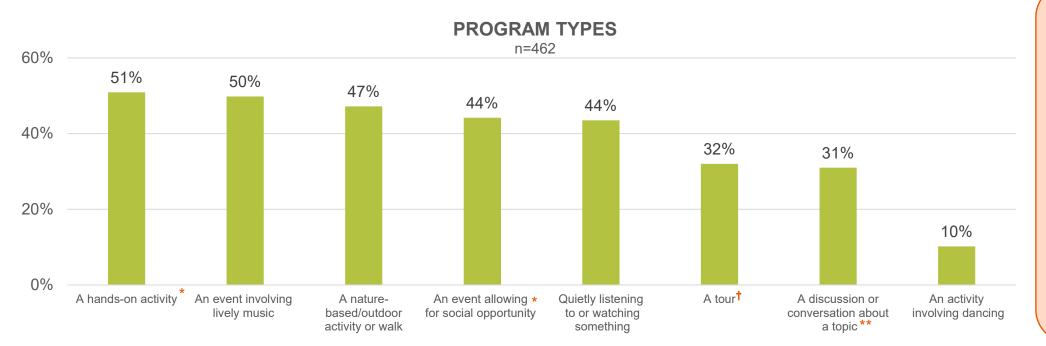
More than half reported they would visit a memory café with their loved one along with other family members. One-quarter reported they would visit with just them and their loved one.





Program Preferences – Activity Types

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



*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 types than those with lesser interest levels

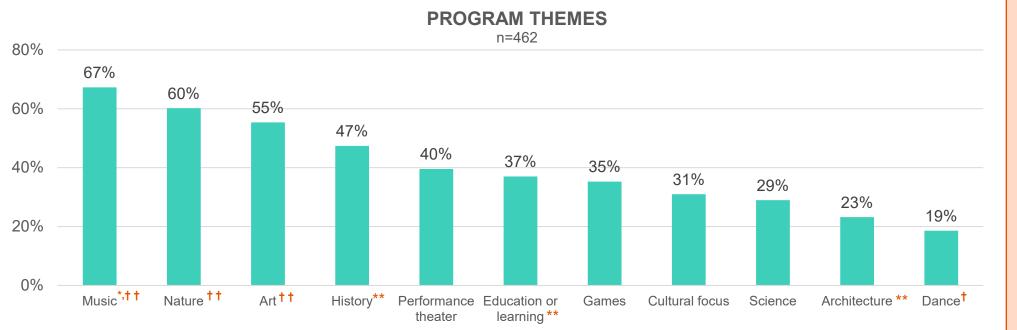
**Those who have loved ones with forgetfulness with age or mild cognitive impairment were more likely to be interested in a topical discussion or conversation compared to those with a moderate diagnosis

[†]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.



*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

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.



Program Preferences – Suggestions

Many suggested similar recommendations of what their loved one may enjoy for a program type or theme.

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

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

SINGLE MENTIONS

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

"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?"

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?

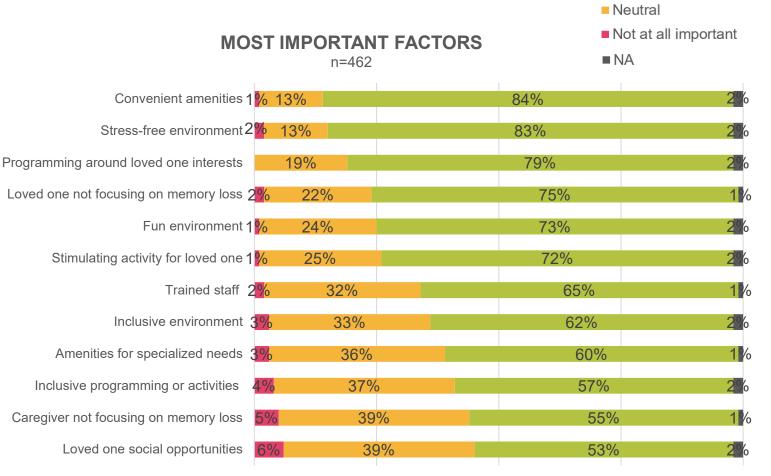


Extremely important

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."

Caregiver social opportunities

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.

17% 47% Caregiver rest or reprieve 35% Caregiver support and connections 13% 50% 36% Programming around caregiver interests 11% 51% 36% Caregiver location proximity 10% 55% 34% Caregiver resource access 47% 45% 50% Loved one location proximity 43% Programming variety 4 49% 45%

LEAST IMPORTANT FACTORS

n=462

22%

Extremely important

- Neutral
- Not at all important

20%

32

■ NA

56%





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

Forgetfulness with age or mild cognitive impairment

- Less likely to rate having trained staff as a very important memory café factor compared to those with any more advanced stage diagnosis
- Less likely to rate specialized amenities as a very important memory café factor compared to those with a more advanced stage diagnosis
- Less likely to rate caregiver support and connections as a very important memory café factor compared to those with any more advanced stage diagnosis
- Less likely to rate caregiver access to resources as a very important memory café factor compared to those with any more advanced stage diagnosis

Moderate or severe cognitive impairment

• More likely to rate caregiver rest and reprieve as a very important memory café factor compared to those with less severe diagnoses

INTEREST LEVEL

Extremely interested in visiting memory cafes

- 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
- More likely to rate having a fun environment as a very important memory café factor than those with lesser interest levels
- 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
- More likely to rate having an inclusive environment as a very important memory café factor than those with lesser interest levels
- More likely to rate having social opportunities for their loved one as a very important memory café factor than those with lesser interest levels



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.

Q: Are there any challenges you as the caregiver may have that would be helpful to factor in for memory café development?

Q: You mentioned there are challenges you as the caregiver 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?



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

Physical mobility limitations (45%)



*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 "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."

"Physical ability — they suffer from physical impairment in addition to cognitive impairment. Needs help walking or would need wheelchair access."

"Easy access to areas and activities with places to rest or wheelchair available."

"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."

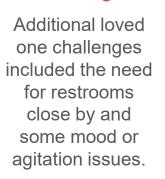
Sensory challenges (10%)

"Loud noises, over stimulating environment, large crowds."

"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."

Q: Are there any challenges your loved one may have that would be helpful to factor in for memory café development?

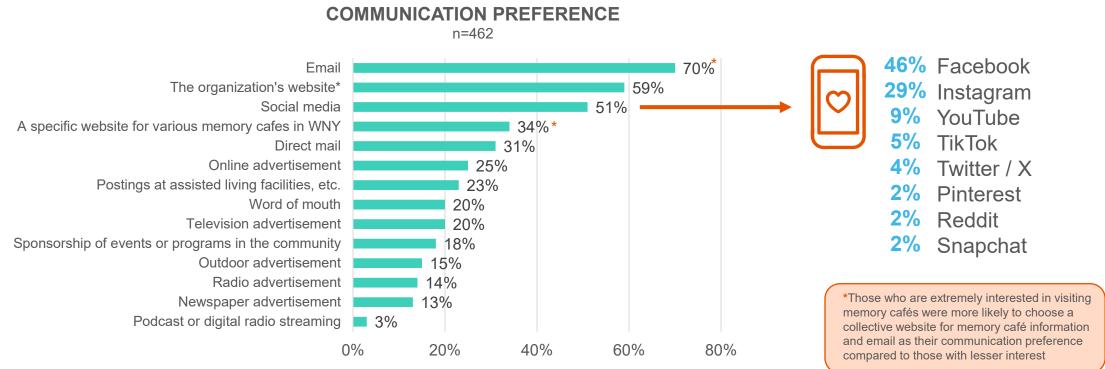
Q: You mentioned there are challenges your loved one may have that would be helpful to know as memory café programs are being developed. Would you please share what the challenge(s) is/are and anything that would help alleviate them?





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.



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

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.

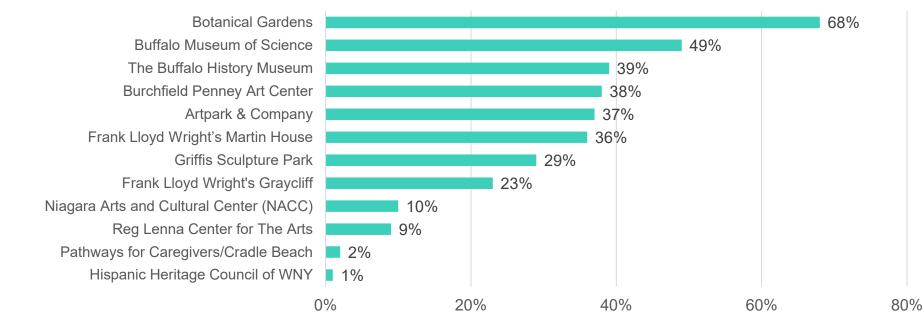


ORGANIZATION VISITATION AND PREFERENCES



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.



ORGANIZATION ATTENDANCE n=462

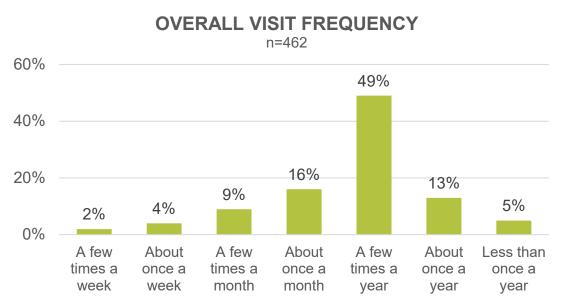
Note: 3% report not visiting any of the listed organizations in the last 2 years

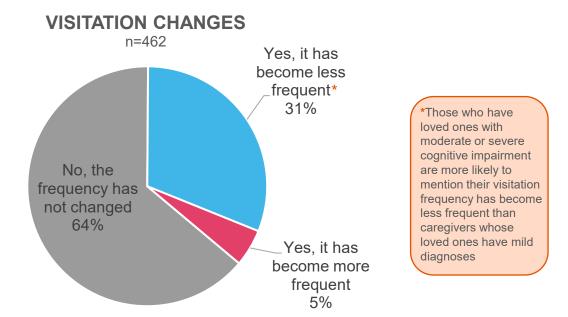
Q: Have you visited any of the following locations in the last 2 years? Please select all that apply.



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.





Note: 3% marked "unsure" for their visit frequency

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

