

ALZHEIMER'S DISEASE RESEARCH CENTER, JACKSONVILLE, FL

Memory Café Startup Guide

A Roadmap for Communities, Organizations, and Other Entities Seeking to Improve the Well-Being of People Living with Dementia and Their Caregivers



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Table of Contents

Introduction: What is Memory Café and Why Is It Important?	3
Getting Started	4
Assessing Needs	4
Leadership, Staff, & Volunteers	5
Selecting a Location	7
Selecting Days, Times, and Frequency	8
Schedule of Activities	9
Marketing & Promotion1	0
Funding a Memory Café1	2
How to Manage and Sustain a Memory Café1	3
The Basics1	3
Ice Breaker Opening1	4
Activities1	5
Refreshments1	6
Managing Challenging Behaviors1	6
Program Evaluation1	7
Memory Café in a Virtual World1	9
Selecting a Virtual Platform1	9
Screening & Preparing Participants for a Virtual Café2	0
Scheduling Considerations	0
The Virtual Program2	0
In-person vs. Virtual?2	1
Appendix2	2

Introduction: What is Memory Café and Why Is It Important?

People with dementia, as well as their family care partners, often experience loss or degradation of their social network. The stigma of memory loss and dementia cause some to withdraw from public life and avoid participation in events or activities they once enjoyed. This leads many to a place of social isolation which, in turn, can lead to depression, boredom, irritability and heightened stress. In some cases, social isolation is followed by more rapid decline and escalation of difficult behaviors, leaving loved ones to manage the burden of caregiving without a robust network of social support.

Socialization is an important component of health and well-being among people with dementia and their family caregivers. Studies show that staying social can help improve quality of life, reduce agitation, and slow the progression of mild memory loss. But people suffering from memory loss and dementia commonly experience negative consequences in typical social settings. Their cognitive difficulties may make social interaction challenging, which can increase anxiety and lower self-confidence. Likewise, family caregivers may feel upset to see their loved one with dementia struggling in social settings, or they may worry about being embarrassed if their loved one demonstrates inappropriate behavior due to their dementia.

A Memory Café offers people with dementia and their care partners the opportunity to enjoy social interaction in a safe, welcoming environment with others who understand them because they share similar circumstances. At Memory Café, people do not need to worry about the social stigma that is often associated with dementia, as they are among others who understand and can offer social support. A Memory Café can offer respite to care partners who may be able to relax knowing their loved one is in a "safe haven"; however, Memory Café is not a traditional respite programs and care partners cannot simply drop off loved ones while they go run errands or take care of personal business.

Memory Cafés take place in many different types of venues – schools, libraries, coffee shops, community centers, or churches, to name a few – but all have in common a commitment to hospitality, engaging programs and activities, and opportunities to connect with others. When considering the development of a new Memory Café, the specific needs/desires of the community must be understood, and an authentic collaborative effort among local organizations and community members should be pursued.

The following guide collects and summarizes information from several published resources on starting and operating a Memory Café, as well as our own personal experiences developing and implementing a Memory Café in the New Town neighborhood of Jacksonville, FL. The New Town community falls within Jacksonville's Health Zone 1, an area subject to the greatest degree of health disparities in the city. Over 90% of community members identify as Black/African American, with over 15% being age 65 or older. At the time we began our Memory Café, little information was available about specific opportunities or barriers to opening and operating a Memory Café in primarily ethnic minority communities. Throughout this guide, we offer sidebar content of anecdotes and lessons learned from our experience in the hope that our journey can assist others who seek to address disparities and help all who live with dementia to live well within their community, wherever that may be.

Getting Started

A Memory Café can be developed by virtually any entity with the knowledge, staffing and interest to do so. The idea can come from individuals, organizations, institutions, civic groups, etc. A key aspect to getting started is understanding if and how such a program meets the needs of community that would be served by the planned Memory Café. Partnerships with local community groups and organizations that serve older adults are essential and can facilitate identifying appropriate locations, programming, and staff. Memory Café leaders should be knowledgeable about dementia and caregiver needs, and aware of community resources for the health and well-being of people with dementia and their care partners. Café leaders should also have sufficient resources available to plan, implement, and sustain a program. Memory Café directors are responsible for the day-to-day operations of planning and running the programs that are the heart and soul of the Memory Café. As such, directors should be capable of scheduling, organizing, and delivering social programs and must communicate effectively with leadership, staff, and participants. Staffing of a Memory Cafe should involve volunteers from the local community who can represent the program and share information about it within their spheres of community influence (e.g., churches, senior centers, social networks, etc.)

Assessing Needs

Memory Cafés should meet the needs of the community they are intended to support. To succeed, it is important to identify local advocates who can help assess the needs and desires of community members.

Our journey to establish a Memory Café in the New Town community began by engaging a neighborhood civic group whose mission was to improve community health and wellness. Through this group, we identified a cadre of "Project Champions" who had specific interest and/or personal experience with people who have dementia. Project Champions were tasked with reaching out to their personal and professional contacts throughout the community to bring together a broad spectrum of stakeholders to participate in focus groups modeled on the Dementia Friendly America toolkit (<u>https://www.dfamerica.org/community-toolkitintroduction</u>). Participants included people with memory loss, family and professional dementia caregivers, neighborhood residents, and members of the local clergy, business, senior services, and medical community.

Project Champions and focus group participants were then invited to a community meeting where results were presented. Although stakeholders saw the need to bring social opportunities for those with dementia and their care partners, other unmet needs were also noted, including the need for community dementia education, caregiver support, and caregiver skill-building. These were rated by the community members as higher priorities, so we worked with local organizations (e.g., Alzheimer's Association, AARP, Mayo Memory Disorders Clinic) to address these needs first, before establishing Memory Café. We believe that the additional contacts and partnerships made while addressing the community's chosen priorities contributed to the subsequent success of our Memory Café.

A formal community needs assessment with focus groups is not required to develop a Memory Café. Some communities instead choose a steering committee of select individuals who can reliably convey what the neighborhood needs. When taking this approach, consider creating a

committee that is small, adequately representative of the community, and mindful of the goals of Memory Café. Consider including the following sectors of the community:

- Someone with mild dementia and their family care partner
- Representatives of organizations with ties to people with dementia (e.g., local Alzheimer's Association chapter, church health ministries, community wellness clinic staff, etc.)
- Persons associated with local government agencies that provide resources for the elderly (e.g., social workers, city services, senior citizens center staff, etc.)
- Local healthcare providers
- Community service clubs/organizations

Your community steering committee can help you decide how broad or limited your Memory Café should be with regard to participants. Many Memory Cafés welcome any community member as long as they self-identify as experiencing memory loss or changes in thinking ability due to dementia. Although a formal diagnosis or other proof of disease should not be required to participate, to achieve the goals of mutual understanding and support, Memory Café should be limited to those who have a reasonable likelihood of having a progressive dementia such as Alzheimer's disease, and not other illnesses such as cancer or stroke.

Leadership, Staff, & Volunteers

Leadership and staffing needs for a Memory Café will vary depending on the size, composition, or setting of the program, but will often require a blending of resources. Community volunteers are an essential component, as is the inclusion of a healthcare professional knowledgeable about aging, memory loss, and dementia on the team. The ability of staff to secure and sustain partnerships and support from community leaders and organizations is also essential and will facilitate the development, promotion, and sustainability of your Memory Café programs.

When selecting people to assist in the development and implementation of a Memory Café, it is important to have a clear vision of the roles and responsibilities of those involved. Below are some definitions and job tasks to consider:

1. Leadership:

A designated individual or group of individuals needs to take primary responsibility for leadership of Memory Café throughout its development and implementation. The leadership team will carry out or oversee the following responsibilities:

- Identify and recruit project champions/steering committee
- Conduct a needs assessment
- Create a Memory Café development plan.
- Create a budget.
- Identify funding sources/opportunities.
- Facilitate training of Memory Café Directors, Staff, & Volunteers.
- Meet regularly with team members to review objectives, progress, successes, and challenges.
- Track deliverables.
- Prepare progress reports for stakeholders.
- 2. Program Director.

The program director will be the face of your Memory Café to the community. They will be present at all Memory Café programs and spend time in the community engaged in

activities that promote and support the Café. A sampling of the responsibilities of a program director includes:

- Complete Dementia Friends (or similar) training.
- Develop a schedule of monthly memory café events, with activity choices informed by participants and tailored to local interests and needs.
- Identify and secure space appropriate in size and accessibility for Memory Café activities.
- Seek and obtain all necessary materials, facilitators, volunteers, equipment, etc. to support café events.
- Seek and establish in-kind contributions and partnerships from local businesses to sustain Memory Café programs.
- Seek community sponsors (and develop written sponsorship agreements that clearly states expectations/limits on marketing to memory café participants).
- Approve all purchases and agreements with program facilitators.
- Collaborate with local partner organizations (e.g., senior centers, churches, other neighborhood groups) to promote Memory Café.
- Advertise program through social media, flyers, church bulletins, interviews for a local radio shows, podcasts, newspapers, etc.
- Actively seek feedback to continuously improve the program and meet the needs of participants.

3. Staff:

The number of people staffing your Memory Café will depend on the size of your program, but plan on needing at least one staff member for every 4-5 attendees. Staff can be paid if funds are available; however, many Memory Cafés run on volunteer support. When selecting people to staff your Memory Café, it is important to find outgoing individuals who are warm and friendly, with good listening skills. They should be able to speak clearly and respectfully with others at all ability levels. They should understand (or be willing to learn about) aging and dementia, and be aware of the common problems encountered by people with dementia and their care partners. They must put the needs of attendees first and recognize the importance of maintaining the privacy/confidentiality of those who attend the program. Memory Café staff may be expected to:

- Complete Dementia Friends (or similar) training.
- Maintain a log of attendees with contact information to follow up with information/reminders about future cafés.
- Encourage attendees to share their experience at memory café with others
- Create flyers and other promotional documents.
- Recruit, train, and coordinate others to assist at café events.
- Administer surveys and program evaluation forms at Memory Café programs
- Track, manage, and document expenses for invoice/audit purposes.
- Assist in marketing and promotional activities.
- Assist program directors and staff with set-up, participant engagement, running activities, serving refreshments, and clean-up.
- Share Memory Café stories through social media.
- 4. Other Volunteers:

Some Memory Cafés enlist other volunteers, such as former caregivers, local students, civic groups, clergy, fraternal organizations, etc. to help out. These volunteers may attend only one or a few programs, rather than being regular "staff". They may assist

with tasks or simply mingle with program attendees to promote social interaction. It is advisable for any volunteer, whether they attend once or multiple times, to view the Dementia Friends training (<u>https://dementiafriendsusa.org/</u>) or similar orientation program prior to volunteering.

The outreach team of the Mayo Clinic Alzheimer's Disease Research Center (ADRC) took the leadership role of the New Town Memory Café. Through partnership with City of Jacksonville Dementia Care and Cure Initiative and ElderSource, grant funding was obtained from the Grace H. Osbourn Endowment at The Community Foundation of Northeast Florida to support the development and implementation of our café. This process helped us hone our Memory Café business plan, facilitated progress, and promoted accountability for meeting goals and achieving deliverables.

Through our prior community focus group experience, our leadership team knew of a motivated and energized group of community residents and leaders, some of whom had expressed particular interest in the importance of social opportunities to combat isolation and stigma among caregivers and persons with dementia.

One individual, a gentleman who was well known in the neighborhood, had a history of involvement in community improvement projects, and whose mother had dementia was selected as Director of the New Town Memory Café. At his request, a co-director was also named and, together, they identified local venues and volunteers. They planned and developed each month's activities and promoted the program throughout the area. As experts on their own neighborhood, they were very well suited to find the right people, places, and opportunities to drive a successful program.

Selecting a Location

Memory Café should meet in familiar, welcoming, easily accessible community location that is safe and comfortable for all. The location should be convenient and afford a private meeting area that is generally quiet, calming, and well-lit so participants can feel at ease and free to interact. There needs to be ample parking for those driving and, if appropriate and possible, the location should be near public transportation for those who prefer not to drive. Locations must be ADA accessible, including the restrooms, which would ideally be located within or immediately adjacent to the café space.

The meeting space should be large enough to accommodate the expected attendance and activity. Keep in mind that attendance may rise once word gets out about the program, so even if only a handful of people show up at the outset you may soon find you need space of 30-40 participants. A small room may be adequate for an activity such as playing Bingo but could become problematic if you plan on hosting a dance or exercise activity.

Tables and chairs should be arranged ahead of time in such a way as to encourage (but not mandate) interaction. Try to avoid setups that seat only two people per table, as this may cue caregivers and their loved ones to sit together and interfere with the goal of promoting social

interaction with other attendees. Ideally, the facility should allow food and beverages to be served, as socialization is often facilitated by refreshments.

Whenever possible, Memory Café should take place on the ground floor of a building, to avoid stairs or crowded elevators. For safety, it is preferable that the space have a limited number of entrances/exits to help guard against wandering. On site-security is a plus, but security personnel and venue staff who manage the space used for Memory Café should be educated about dementia and the importance of a hospitable, non-stigmatizing environment.

Cost may be a consideration in selecting a location. Many public buildings have meeting rooms that may be available at no charge, although some may request a liability waiver or statement of insurance coverage. Libraries, churches, senior centers, schools, and actual cafés/restaurants during off-hours are all potential options. Be creative in selecting the location, keeping in mind the key aspects of comfort, accessibility, and safety.

The first meeting of the New Town Memory Café was held in a small health food restaurant. The business was locally owned and operated, and the owner made the space available at a time when the restaurant would normally be closed. No fee was charged for use of the space, but participants were expected to purchase their own food. The owner was present during the meeting and gave a brief presentation on the benefits of healthy foods. The remainder of the time was spent enjoying snacks, mingling, and getting to know one another through informal chat and minimally facilitated small group discussions

Although well-appointed, accessible, and welcoming, the space turned out to be too small for comfortable socializing. Additionally, the expense of food purchases was unsustainable.

In seeking an alternate location, our program directors learned of a large, furnished activity room at a public library that was available for public booking at no charge. The space was large, calm, well-lit, and comfortable, with on-site security. Food and beverage were allowed, parking was plentiful, and the building was conveniently situated on a public transportation route. Overall, the perfect venue for Memory Café.

Selecting Days, Times, and Frequency

Memory Cafés are typically held once a month. The specific times, dates, and frequency of Memory Café meetings should be based on several factors, including availability of space and convenience for participants.

1. When to hold Memory Café.

Consider traffic patterns, public transportation schedules, and availability of the care partner when selecting time and day for Memory Café. Cultural considerations may also be a determining factor. If focusing on a particular demographic it may be advantageous to consider a short survey to avoid scheduling conflicts that could make it difficult for people to attend. Always keep in mind the needs of the participants.

Since Memory Café requires participation by the person with dementia and their care partner, weekends may be convenient for those whose care partners are still working. Weekend availability of certain venues like public libraries may have flexibility; however restaurants may be less eager to host such an event on a weekend unless it is held at a traditionally "light" time of day outside the expected lunch and dinner rushes.

Considering that a subset of people with dementia become confused and agitated as evening approaches (i.e., "sun-downing") it may be best to avoid scheduling Memory Café for late afternoons or evenings. It is also important to consider timing of Memory Café sessions as they may relate to mealtimes. If the Memory Café schedule overlaps with a major meal, advertising should clearly indicate whether a meal will be served. In the interest of time, socialization, and budget, it is preferable to offer light refreshments at Memory Café programs rather than a full meal.

The timing for Memory Café should remain consistent from month to month to allow participants to get into the habit of coming regularly and being able to anticipate the next meeting. It is therefore important to look ahead on the calendar and plan accordingly.

2. How Long Should a Memory Café Program Last?

Ideally, Memory Café sessions should last no more than 2 hours. This seems to be a good amount of time for people to arrive, settle in, and enjoy some fellowship, activities, and snacks before heading back home. Programs lasting under two hours may feel rushed while programs over two hours may be perceived as exhausting.

3. How Often Should Memory Café Be Offered?

This is best answered based on resources, staff/volunteer availability, and interest of attendees. In most cases once a month will be sufficient, but it may be best to let the community decide the frequency based on their needs. Frequency can also be driven by capacity. If the venue can only accommodate half the number of people who would like to attend, consider running the same program twice a month.

The New Town Memory Café is held on the second Saturday of each month at 2:00 in the afternoon. The day/time was selected after asking caregivers who participated in our focus groups about their preferences and potential conflicts throughout the week. We learned that Saturday afternoon was a popular choice because many caregivers get their shopping done in the morning and were often looking for something to do after lunch.

Our Memory Café program runs from 2-4pm and provide light snacks to bridge the gap between lunch and dinner. Ending the program by 4pm allows time for attendees to return home during daylight hours and with sufficient time to prepare dinner.

Schedule of Activities

Once a venue and timing been determined, it is important to plan how the program time will be utilized. A Memory Café program should be simple and offer activities that hold wide appeal. It should move along at a relaxed pace and remain mindful of the main purpose of the activity - to maximize socialization and enjoyable interaction.

A sample program schedule might include:

- Welcome
- Introduction of staff/volunteers (and their roles)
- Housekeeping items (e.g., location of rest rooms, silence cell phones, agenda)
- Ice breaker activity
- Program (e.g., activity, performance, speaker)
- Refreshments & Socializing
- Wrap up

More detailed information about these program components are provided later in Section III of this manual.

Marketing & Promotion

Despite the excitement and enthusiasm that Memory Café leaders, directors, and staff may feel about their program, it is important to recognize the barriers exist that may prevent people with memory loss and their care partners from attending. The widespread stigma associated with dementia, lack of familiarity with the Memory Café brand, and lack of knowing how a loved one with dementia might behave in a new setting may negatively impact interest level and participation, especially early in the implementation of Memory Café.

1. Who Should Come to Memory Café?

Before work begins on marketing and promotion of your Memory Café, you should give thought to your target audience. Memory Café should be reserved for people who have memory loss due to known or suspected dementia, as well as the family members who provide for their care. Alzheimer's disease (AD) is the most common cause of dementia in the elderly and people with AD and their care partners will likely reflect the majority of participants. People with dementia due to other causes, including Lewy Body disease and Frontotemporal dementia may also participate if the behavioral symptoms associated with these conditions are managed.

The prime target audience for Memory Café is anyone with dementia who can negotiate an accessible physical space and would enjoy being among a group of people. If the individual requires assistance with ambulation, medications and/or using the restroom, the care partner will need to provide for these needs, as staff/volunteers do NOT assist with personal care. Those with mild to moderate disease who are living at home but have begun to withdraw (or have withdrawn) from community life are ideal candidates for Memory Café. People with very early/mild disease may not require Memory Café to socialize whereas people with more severe dementia may not be able to engage others appropriately; however, unless someone's behavior is disruptive, all should be given a chance to see if Memory Café is right for them.

All marketing and promotion of Memory Café should clearly explain the purpose and goals of the program. It should also be made clear that Memory Café is <u>not</u> a daycare for caregivers to drop off their loved ones while they accomplish tasks or obtain respite. Emphasis should be placed on the goal of providing a safe and welcoming place for caregivers and their loved ones to socialize with others and engage in fun activities together.

Even with the clearest messaging it is possible that an individual with dementia may arrive without a care partner, or vice versa. For a participant with dementia who was "dropped off," a volunteer should be assigned to engage the individual and monitor their safety throughout the session. Attempts should be made to reach the care partner. When the care partner returns, Memory Café staff should explain the rules and ensure that both the person with dementia and caregiver understand they are welcome to attend together. If other resources (e.g., respite care) are needed try to understand the needs and provide appropriate referral information. Similar steps should be taken if current caregivers seek to attend Memory Café without their loved ones who have dementia.

2. Promoting a New Memory Café

Much groundwork needs to be done in advance of the launch of a Memory Café. Community leaders and stakeholders should be educated about the goals of Memory Café and asked to help communicate this information with local groups and others within their sphere of influence. Memory Café directors should spread the word to local healthcare providers and organizations that serve elders. Flyers are effective communication tools and can be posted in places where older adults tend to visit, including senior centers, primary care physician offices, churches, grocery stores, public libraries, retirement communities, etc.

There are numerous other methods of marketing that can be leveraged to promote Memory Café. These include reaching out to local reporters to provide stories about Memory Café to run in newspapers, radio shows, and podcasts; giving an invited talk (or post-presentation announcement) at meetings of local clubs, organizations, or health ministries; or advertising in church bulletins or newsletters distributed by local chapters of the AARP, Alzheimer's Association, and other national organizations that serve seniors.

Decisions regarding where and how to advertise Memory Café should be determined by the community or demographic you wish to reach. Since the concept of a Memory Café may be confusing to the uninitiated, it can be worthwhile to get the word out through interviews with trusted local media outlets to explain the concept and address common questions.

Our Memory Café in New Town was intended to address dementiarelated disparities within a traditional under-served African American neighborhood. Our advertising choices reflected this goal by promoting stories about Memory Café in a neighborhood newsletter and communitybased newspaper. We posted flyers at a neighborhood community center, placed notifications in church bulletins, and leveraged community-based social media posts. We also relied on word of mouth from our project champions and program staff.

This approach was efficient, cost-effective, and tailored to the mission of our Memory Café. Once our program launched, our promotional materials often include photographs of participants socializing or engaging in fun activities (always making sure ahead of time that those photographed agree that we can use the photos in marketing the program). 3. Sustainability

Marketing efforts should continue even after Memory Café has started, to continuously reach new people who may benefit from the experience. All the strategies used at the launch of a Memory Café can continue to be utilized. Additionally, the café director, volunteers, and participants should be encouraged to seek opportunities to speak with others who may be worried about their memory or who may have recently received a diagnosis of dementia. For example, local dementia support groups and dementia outreach/education organizations such as the Alzheimer's Association may provide opportunities for you to present information about your Memory Café to an interested audience.

It is also important to touch base with Memory Café participants with reminder phone calls, emails, or postcards to make sure they are aware of the next meeting date/time. If you notice that participants have stopped attending, it may be helpful to reach out to them to better understand the degree to which their needs were met (or not met) by the program, and if there are barriers to attendance you have not yet considered. This feedback may provide opportunities to improve the Memory Café experience for all.

Funding a Memory Café

Memory Café is typically not very expensive to operate but there are some anticipated costs that will require a source of funding. If a funding source is not already secured, one of the first tasks of leadership will be to identify sponsors and obtain funding commitments to cover expenses.

The budget for every Memory Café will differ depending on the location, activities, and number of people who are willing to volunteer their time or provide in-kind donations. Costs that will likely be incurred by most programs include:

- Print costs for marketing/promotional brochures, flyers, etc.
- Activity supplies, such as games, puzzles, music player,
- Refreshments
- Tableware, such as tablecloths, plates, cups, napkins.
- Venue rental
- Payment to activity leaders (if using an outside instructor/entertainer)
- Program director stipend
- Office supplies
- Program evaluation costs

Funding can come from a wide variety of sources. Many local organizations (community foundations, service clubs, civic groups) have grant mechanisms that can be leveraged to support Memory Café. Individual and corporate donors can be sought for financial support or inkind donations of food, supplies, and/or space. Memory Café leadership and Program Directors may need to be creative and proactive in seeking funding sources, and should be realistic in their ability to ensure long-term sustainability. The original annual budget we proposed for the New Town Memory Café is presented below as an example of the anticipated costs of running a year-long program. In addition to the expenses described earlier, we also budgeted for the cost of car service in anticipation that some participants may be unable to drive or utilize public transportation. Over the course of program development and implementation, costs shifted across budget lines, as some expenses were lower than anticipated (e.g., venue and transportation fees) while others increased beyond what we originally planned (e.g., director stipends). We also did not budget for mileage costs incurred by Memory Café staff scouting potential locations, picking up supplies and refreshments, and visiting groups around town to speak with them about Memory Café.

Expense	Amount
Program Director	3000.00
Office Supplies	750.00
Activity Supplies	1300.00
Activity Facilitators	3600.00
Refreshments	1800.00
Facility/Venue Fee	1200.00
Transportation Stipends	1200.00
Program Evaluation	1250.00
Promotion/Marketing	500.00
Total	13,000.00

How to Manage and Sustain a Memory Café

The Basics

Operations may vary depending on the location and activities planned for a specific Memory Café; however, the following general considerations are presented to help manage some of the core logistics:

- Volunteers should be posted at the Memory Café entrance at least 15 minutes before the scheduled start time to greet people who arrive early. They should be prepared to answer questions from new participants or direct such people to the program director or other volunteer. Volunteers at the door should be vigilant to caregivers who misunderstand the intent of Memory Café and may think they can drop off their loved one and leave.
- At least one volunteer should remain at the entrance throughout Memory Café to assist participants who may come late, direct guests to facilities (if located outside the activity room), and guard against anyone wandering away.
- As people arrive, volunteers should orient new participants to the space and the program schedule and introduce them to other participants. Some Memory Cafés place large piece puzzles out on tables for people to have something to do while waiting for the program to start. Others will offer drinks or snacks at the beginning and encourage people to mingle.

- A sign-in sheet should be used to monitor attendance rates and to collect contact information from those participants who wish to receive reminders about upcoming Memory Café dates, newsletters, information about research opportunities, etc. A contact list will also facilitate program evaluation in the event some participants are not present at the time survey data are collected.
- It can be helpful for all participants, including Memory Café directors and volunteers, to wear a name tag bearing their first name. These name tags can be saved and used again, or disposable tags can be used.
- If there is a plan to take photos of Memory Café for promotional or reporting purposes, participants coming for the first time should complete a photo permission sheet.
- Some people may want to socialize but feel self-conscious or otherwise uncomfortable doing so. Memory Café volunteers should be on the lookout for such individuals and can play an important role in facilitating social interaction. Volunteers can strike up a conversation themselves or introduce attendees to each other. Always be respectful, however, of the autonomy of attendees who indicate they do not want to socialize at the moment.
- Give participants a 15-minute warning prior to ending Memory Café so they have time to prepare to leave.
- Set up informational brochures and handouts that may be of interest to participants that they can collect on their way out. Items may include a calendar of upcoming Memory Café dates and times, dementia education materials, caregiver resource information, etc.

Ice Breaker Opening

Ice breakers are brief activities to help ease tension or awkwardness and engage participants in fun, easy conversation. When participants don't know each other, an icebreaker helps each person get to know something about the other. A well-selected icebreaker is something most anyone can talk about and helps people feel comfortable enough to speak up. Even if participants already know each other from past café attendance, an icebreaker is still an effective way to warm up the conversation and help people engage with each other.

The ice breaker exercise is intended to create a supportive and welcoming environment for all. Everyone should get a turn but if someone declines or is obviously uncomfortable, they should not be forced to participate. In fact, some may feel connected to the group just by listening.

There are many websites with lists of different types of effective ice breakers to explore, but some examples of simple ice breakers appropriate for a Memory Café might include:

- What was your first car?
- What is your favorite dessert?
- Where did you grow up?
- What is your favorite song? How does it go?
- If you could speak with a famous person, who would it be?
- What is your favorite season of the year and why?
- What is one of your most prized possessions?
- If you could go anyplace in the world, where would you go?
- What was your favorite subject in school?

Activities

Memory Café activities and programs can vary greatly depending on the interests of participants and the resourcefulness and creativity of the coordinator and volunteers. Most Memory Cafés with scheduled activities do not program them for more than an hour. Some activities are best set for 30-45 minutes. If doing a physical activity, it might be best to do several brief (10-min) programs broken up by socialization or seated activity.

Talking with participants about programs of interest is helpful. Informal feedback about activities can be solicited at any time and can help determine which activities to repeat and what new activities to offer. Inviting professionals such as musicians, artists, yoga instructors etc. to lead Memory Café activities can be rewarding for all, but the program director should be sure these activity leaders are properly educated and advised of their audience well in advance. It should be made clear that participants are to be treated with respect as adults, and that to the degree possible, the program should be interactive as well as entertaining.

A sampling of possible Memory Café activities is listed below. Before booking a program, it is important to first check with the venue to make sure the activity is permitted.

- Games (Bingo, Card Games, Puzzles)
- Arts & Crafts
- Dancing
- Relaxation & Yoga
- Popular music/sing-alongs from bygone years
- Magicians & Comedians
- Historical Conversations
- Art Appreciation Discussions
- Planting a Container Garden
- Participant Sharing (travels/adventures from their past, stories from their "memory box").
- Helping others (making back to school baskets or food baskets for those in need).
- Field trips, such as meeting at a Museum, Nature Center, Zoo, etc. Many venues will have free or discounted programs for seniors that could be modified to accommodate persons with dementia.

Activities that our Memory Café participants tell us they enjoy the most are playing Bingo and dancing and singing along to "oldies" music. They also very much enjoy the occasional "field trip" we have offered during months that our usual room at the public library is unavailable. On one such occasion, the Jacksonville Zoo and Gardens provided a free meeting room and train ride around the park for the (already discounted) cost of admission. On another occasion, a local organization (Edward Waters College) donated tickets for Memory Café to be held at a local art museum, complete with private group tours led by staff who have received Dementia Friends training.

Regardless of the specific activity, our Memory Café participants are delighted when they arrive to a room that is decorated along a holiday theme. Hearts posted around the room and flowers on the table set the theme for our Memory Café Valentine's Day "dance", while thrift store decorations and staff dressed up in silly costumes brought much laughter, joy, and reminiscences during a Halloween Memory Café costume party. Conspicuously absent from the suggested list of activities for Memory Café are informational lectures about dementia. Although community education on dementia is important, it is not the goal of Memory Café, which strives to give people with dementia and their care partners a break from focusing on the disease. Of course, participants and their care partners are welcome to ask questions, share resources, and offer support to one another while socializing, but those interested in hearing a formal talk about dementia are provided information on local lectures.

A Note on Personal Sharing: It is helpful to give participants advance notice of programs that plan to focus on personal sharing as the primary activity. This will allow participants time to plan for the program and search for something to bring with them to facilitate their story. Giving advance notice also helps to avoid situations where participants feel put on the spot or caught off guard. For example, if the next Memory Café will be held close to Veterans Day, participants can be informed in advance that the program that day will be about veterans and those who would like to share their own stories and memorabilia will be invited to do so. This gives participants and care partners sufficient time before the next Memory Café to talk things over, select a story, and find something that they may wish to show.

Refreshments

Always check first with the venue about food restrictions and if cleaning fees could be incurred. If your Memory Café is held in a food establishment, be aware of whether there is an expectation of a minimum amount of food and beverage purchases required to secure the space, and how you will cover any discrepancies that may arise.

If you may bring and serve refreshments on site, small finger foods tend to work best. Fruit and vegetable trays, finger sandwiches, cookies, pastries, and other foods that hold up well at room temperature are good options. This allows people to enjoy their snack while moving about the venue and mingling with others. Holiday themed refreshments and tableware can brighten the space and serve as conversation starters but be mindful that not all participants may celebrate certain holidays.

Although called a <u>café</u>, there is no requirement for coffee, tea, or other hot drinks to be served at your Memory Café. Remember, the focus is on socialization and fun activities, not on food and beverage. If you would like to serve hot coffee or tea, consider using cups with lids and serve the beverage at a temperature that will not cause injury if spilled. Small canned or bottled drinks are preferred over cups to minimize mishaps as people carry their drinks and/or mingle with others. If the venue does not have a refrigerator, consider investing in a portable cooler to store beverages, ice, and foods that may need refrigeration.

In the interest of safety, Café staff should always use gloves when serving food. Hand sanitizer should be made available to all attendees. Also be sure that food is not left out too long.

Managing Challenging Behaviors

Although family care partners are always present at Memory Café, it is important that staff understand the typical behavioral challenges that may arise in someone with dementia. Beyond understanding, staff should also have some level of training to be able to assist in managing problem behaviors, if warranted. It is often best, however, to seek guidance from the person's care partner first, rather than assume assistance is needed.

Some individuals with dementia may be prone to wandering or engage in socially inappropriate ways. Fear and lack of familiarity in new settings can cause some to be overly anxious or act out in disruptive ways. In rare instances, the individual may act out aggressively. Caregivers are typically able to manage their loved one's problem behaviors but may require a quiet place away from the group, or other forms of assistance from café staff.

If a participant's behavior is disruptive or otherwise deemed detrimental to the well-being of other Memory Café participants, it is within the rights of the program director to request the caregiver remove the individual. If the behavior recurs at subsequent visits, the director and staff should evaluate whether simple changes can be made to the environment to address the problem. If the disruptive behavior cannot be managed reliably, however, staff should be prepared to refer the caregiver to alternative services that can support the greater needs of their loved one.

Participants should not attend Memory Café if they feel unwell, as it will be difficult for them to enjoy the program and they may risk the health of other participants. As dementia progresses, caregivers will need to evaluate whether the informal social environment of Memory Café continues to meet their needs and the needs of their loved one.

Caregivers who no longer have caring responsibilities may express interest in continuing to attend Memory Café. We recommend that they should not be discouraged from doing so initially; however, after a brief period of time a more appropriate service should be sensitively suggested, since the focus of Memory Café is to offer ways for <u>both</u> the person with dementia and their caregiver to enjoy time together. If there is opportunity and the fit seems good, the former caregiver may be considered for a role as a volunteer rather than a participant. Referral to other programs or support networks specifically for former caregivers, however, may ultimately be the best option.

Program Evaluation

Community interest and engagement in Memory Café can be informally assessed simply by recording and monitoring attendance rates. A more formal process of program evaluation is also recommended, however, to systematically collect information about program activities and objectives, monitor progress towards reaching and achieving the goals of the program, and communicate outcomes to key stakeholders. Spending time up front in consideration of the outcomes you seek and methods you will use to evaluate the success of your Memory Café is time well spent.

- 1. Key components of a Program Evaluation plan include:
 - <u>Program Description</u>: Describe the mission, vision, goals, and objectives of your Memory Café. Think about overall goals as described in this manual, as well as specific needs of the community or demographic you are targeting for your program.
 - <u>Evaluation Design</u>: How will you know how well your program meets your stated goals and objectives? Surveys are useful, commonly implemented tools for this purpose. For example, you may want to measure how attending Memory Café addresses social isolation. To accomplish this, you could find or create a questionnaire that measures loneliness and ask participants to fill out the survey

before their first Memory Café attendance (i.e., pre-test) and again after having attended a certain number of sessions (post-test). Alternatively, you could omit the pre-test and ask participants to rate the degree to which they feel their participation Memory Café has improved their socialization. In addition to its impact on social isolation, one could also measure how Memory Café reduces stigma of dementia, helps relieve caregiver stress, etc.

- <u>Key Data</u>: Identify the specific outcomes you want to measure and think of the types of questions you can ask to measure those outcomes. Plan when and how often you will collect data. Be sure to let participants know in advance if/when you will be asking them to provide information about the program. If collecting data during a Memory Café program, be sure sufficient staff/volunteers are on hand to assist participants.
- <u>Summarize and Communicate Results</u>: Share your evaluation results with sponsors and stakeholders, including your Memory Café participants. Plan next steps based on the data you collected.
- 2. Participant Satisfaction & Suggestions. Feedback from participants is important and, in many cases, sufficient for program evaluation purposes (as opposed to measuring specific outcomes as noted above). Although success can often be judged at least in part by participation, running a Memory Café is a learning process and it is therefore important to remain open to feedback to ensure the needs of your participants are met. Feedback can be obtained informally by simply checking in with participants from time to time regarding their satisfaction with the program, ideas for new activities, etc. At least once a year, however, it would be advisable to pursue a formal, anonymous survey where various forms of participant bias are minimized.

Our Memory Café directors made efforts to stay in contact with participants between Memory Café visits, often making a quick call to remind participants of the next café and solicit informal feedback about how well they enjoyed the previous café. Hearing what participants liked and did not find enjoyable allowed the directors to shape the content and agendas for subsequent meetings.

After a while, we also collected formal survey data. The brief set of questions (reproduced below) was derived from formal surveys from the literature that measure dementia stigma and social isolation. Participants who were not in attendance at the time the survey was completed were called by program staff to solicit their feedback.

Attending Memory Café, I feel:	Always	Often	Sometimes	Never
Comfortable	1	2	3	4
Respected	1	2	3	4
Left out/ignored	1	2	3	4
Lonely	1	2	3	4
Supported	1	2	3	4
Embarrassed	1	2	3	4
Stressed	1	2	3	4
Joyful	1	2	3	4
Part of a community	1	2	3	4

3. A Note on the Use of Surveys: Participants come to Memory Café to socialize and have fun, so take care not to overburden attendees with too many surveys. Also, keep in mind that half of your participants have some level of dementia and may become anxious or confused when trying to complete a survey. Try to keep questions as direct and simple as possible. Be sure they are brief and that the print is large enough to read comfortably. It is best to administer surveys at the beginning of a session instead of towards the end when participants may be more fatigued and wanting to go home.

Memory Café in a Virtual World

In spring 2020, the COVID-19 pandemic changed life as we know it in many ways. Not surprisingly, Memory Café was an early casualty in many communities - after all, a program that promotes close interpersonal interaction and socialization cannot easily survive in an environment where social distancing and isolation are necessary to maintain health and physical wellness, especially when the target audience of older adults is also the most vulnerable to infection.

As virtual platforms began to appear and people of all ages became increasingly comfortable interacting via technology, new opportunities for Memory Café emerged. Some organizations and communities embraced these opportunities and quickly transitioned their in-person Memory Cafés to virtual programs. This transition was likely most successful in communities where older adults have resources to support their ability to fully engage in a Memory Café program (e.g., large screen electronics/tablets, high speed internet connections), as opposed to populations without such resources. Nevertheless, for those who can participate online, a virtual Memory Café offers some degree of social connectedness (and health safety) that might otherwise be missing in the absence of an in-person Memory Café program.

Several aspects of a virtual Memory Café will be the same as those described above for inperson programs, while others may not be necessary (e.g., location, refreshments). Below are some considerations that are unique for setting up a Memory Café in a virtual environment.

Selecting a Virtual Platform

Working with a well-established platform featuring relatively easy access, security, and stability is mandatory. Most virtual platforms offer online tutorials that can help you choose the one that will best serve the needs of your Memory Café programs.

While many virtual Memory Café participants may be technically savvy there may also be many participants requiring guidance. The Zoom platform has become popular among older adults who have been using video conferencing to stay connected with family and friends during the pandemic. Zoom also appears to be very popular among currently existing Virtual Memory Cafés.

Regardless of platform, virtual Memory Cafés often require people to sign up in advance for their meeting and, to maximize privacy, will allow access only with use of a passcode. Signing up for Memory Café in advance also gives participants time to learn about the platform and how to use it, if it is one with which they are unfamiliar.

Screening & Preparing Participants for a Virtual Café

When promoting a virtual Memory Café, it may be helpful to screen participants prior to inviting them to attend the Virtual Memory Café. This can consist of a very brief virtual discussion to ensure those wanting to join have the appropriate means to participate, understand the purpose of Memory Café, and demonstrate behavior, communication skills, and sufficient hearing acuity to maximize participation and minimize frustration during online group activities. The care partner's thoughts and interactions with their loved one during this discussion can also reveal important indicators of success.

Consider using the time to also explore the likes and dislikes of potential participants, to help generate ideas for program content and online group activities. Some Memory Café programs have leveraged the virtual technology to open their program to participation by extended family members of the person with dementia. These family members may live out of town or otherwise not participate in the daily caregiving responsibilities. Although this may be fun for the extended family, care should be taken not to overlook the goals of your Memory Café and the impact the presence of these extra attendees may have on other participants.

All participants should be sent a "virtual" etiquette guide in advance of each Memory Café. They should be encouraged to "practice" on the platform site before they attend Memory Café if they are not already familiar with the site's features. This will make for fewer glitches and a better Memory Café experience for all involved.

Scheduling Considerations

Café Connect®, an online directory of virtual Memory Café programs, maintains a calendar of dates and times for programs across the country and links to each Café where interested individuals can email the program director for information. All program times are listed as Eastern US time zone regardless of the actual location. Taking time zone differences into account, it appears that most communities hold their virtual Memory Cafés from mid-morning through mid-afternoon, local time.

Virtual Memory Cafés rarely last two-hours like their in-person counterparts. Given factors related to screen fatigue and challenges associated with maintaining attention and focus to virtual content, most virtual Memory Café programs are scheduled for 75-90 minutes and rarely overlap the noon lunch hour.

The Virtual Program

Virtual Memory Café programs typically follow the same schedule as an in-person program, namely:

- Welcome & Introductions
- o Announcements/Orientation to Program Agenda
- o Ice Breaker Activity
- Program Activity
- o Wrap up/Plans for Next Memory Café

Active socializing is difficult during virtual meetings because only one person can speak at a time. Although many virtual meeting platforms have private chat functions where people can

message each other through text, this may be cumbersome and frustrating, especially for those who may have difficulty using a keyboard.

Most activities planned for in-person Memory Café can be transitioned to a virtual format with forethought and planning. Many programs translate well (e.g., Sing-alongs, Participant Sharing, Shared History Discussions, etc.). For hands-on activities like arts & crafts, Bingo, Memory Box creation, or garden projects, a supply list should be provided to participants in advance. To save caregivers the burden of going out for supplies, consider activities where supplies can be sent electronically (e.g., printable Bingo cards) and projects that can be completed with items commonly found in the home. Sending/delivering supplies may also be possible, depending on the size of your Memory Café and the cost/logistics of your delivery method.

One advantage of virtual Memory Café is the ability to provide content that may be better suited for an online experience than an in-person program. For example, the internet is home to a wide variety of virtual tours of museums, gardens, national parks, heritage sites, and other points of interest around the world that can be incorporated into Memory Café programs and discussions. If including such tours in your virtual program, remember to be selective and brief, keeping in mind that the emphasis should be less on the tour itself and more on its ability to generate subsequent discussion, comments, and reminiscences among participants.

In-person vs. Virtual?

As pandemic restrictions ease, some may wonder if it is better to return to in-person Memory Cafés or to remain virtual. Like most decisions in this manual, the answer to this question resides in the needs and desires of the specific community your Memory Café serves, and the goals you have set out. If your Memory Café is currently in operation, it will be important to canvass participants for feedback, maybe setting aside some time during a program to discuss what participants like and don't like about in-person and virtual offerings. If you are planning a Memory Café, consider the pros and cons of each format, including accessibility vs. technologic resources and sophistication of your intended participants, cost efficiency (if holding Memory Café in a paid space), and other factors that may be specific to your target community. Finally, it is worth noting that, as the pandemic has begun to subside, some Memory Cafés have decided not to choose, but have instead pursued hybrid models, offering small in person programs as health guidance permits, while maintaining their virtual option as well.

> The COVID-19 pandemic forced our Memory Café to go on hiatus after being up and running for less than a year. The size of our café was still relatively small (10 dyads), with most members living within and around the same neighborhood, so in early months of the pandemic we created and delivered gift baskets containing a variety of activities, snacks, and words of support to maintain contact as we considered options.

Participants told us the thing they valued most about Memory Café was the in-person social interaction and fellowship. Regrettably, there was little enthusiasm for a virtual model and when a pilot session was offered, only about half of our regular Memory Café members participated, all of whom subsequently reiterated their strong preference for in-person meetings. We plan to resume such activities once it is safe to do so.

Appendix

Memory Café References & Resources

Dementia Society of America offers information about in-person and virtual Memory Café programs across America, as well as in Canada, Australia, the U.K., and Brazil. The website maintains resources for caregivers and includes a search function to find a Memory Café in or near your local area. A separate directory for Virtual Memory Cafes lists programs that can be accessed from home, either by computer or phone.

- Memory Café Directory: <u>https://www.memorycafedirectory.com/memory-cafe-directory/</u>
- Café Connect (Virtual): <u>https://www.memorycafedirectory.com/cafe-connect/</u>

Percolator Memory Café Network: Jewish Family & Children's Services of Massachusetts offers information and quarterly meetings to organizations and individuals who would like to start and sustain their own memory café. Resources on their website include videotaped webinars, a national virtual memory café directory, a memory café development toolkit, and downloadable templates of helpful materials that can be edited to fit any program. <u>www.jfcsboston.org/Percolator</u>

Dementia Mentors is an organization that strives to keep those living with dementia social, even if circumstances dictate that they do so virtually, from the comfort and safety of their own homes. They are a resource for virtual memory cafes. <u>https://www.dementiamentors.org/</u>