

# MEMORY CAFÉS: An Environmental Scan

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## Executive Summary

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Memory cafés are designed to offer a safe, comfortable, and stimulating gathering space for persons with Alzheimer’s disease and related dementias (ADRD) and their caregivers. Dementia is an overall term for a particular group of symptoms including difficulties with memory, language, problem-solving and other cognitive skills that interfere with a person’s ability to perform everyday activities. Among the many causes of dementia, Alzheimer’s disease is the most common: According to the Alzheimer’s Association, 5.8 million people, or 1 in every 10 people age 65 and older, are currently living with a diagnosis of ADRD in the United States; that number is expected to increase to 14 million by 2050. Memory cafés offer social support and connection, socialization, health, and wellbeing to participants (at any stage of disease progression) in a welcoming environment. The growth of memory cafés throughout the United States and in other countries speaks both to the critical need they meet and the unique supports they provide.

The primary goals of this environmental scan are to:

- Define and describe memory cafés including their core characteristics and geographic presence
- Summarize the demonstrated benefits of memory cafés for participants and caregivers (as identified in the literature)
- Articulate the effective components and best practices of cafés and offer practical guidelines and tools for their implementation
- Identify drivers of successful memory café expansion
- Explore potential applications of the model with other populations, including isolated older adults, rural older adults, and caregivers.

In Section II, we provide an overview of memory café characteristics and the populations they serve. Cafés may take place in a number of different community venues, including libraries, coffee shops and restaurants, houses of worship, performing arts and other community centers, senior centers, assisted living centers, and other locations. Memory cafés usually meet for two hours once or twice a month and operate on a drop-in basis. Regardless of where they are held, cafés share a commitment to offering hospitality, refreshments, and interesting and engaging programs. Cafés provide a setting to listen to music, sing, play games, engage in the arts, socialize, and share community with those living with memory loss and other cognitive challenges. Many cafés request that guests bring their care partner, whether it is a friend, spouse, other relative, or a paid caregiver.

A clinical ADRD diagnosis is not required to attend a memory café. In the United States, ADRD is typically not a focus of organized group discussion at memory cafés since cafés are intended to provide a break from focusing on disease and disability; medical concerns or memory-related topics are usually not part of programming. Still, memory cafés are designed to engage attendees in cognitive activities in order to improve memory and brain health. The goal is to keep attendees mentally and socially active, which research shows is protective of brain health (see “Section III. “Benefits of Memory Cafés”).

Caregivers do not “drop off” their loved one at a memory café. Rather, the caregiver and care recipient have opportunities to enjoy activities together. Because memory cafés incorporate care partners along with participants into their services, they are not traditional respite programs, even if

they might offer a form of respite; the social and creative time they offer can function as a kind of “safe haven” for caregiver respite. In this way, memory cafés support a broader definition of respite.

While there are not strict parameters for what characteristics constitute a memory café, some characteristics are common among cafés. They are typically staffed by an individual (one consistent person) who acts as host or facilitator and who can offer guidance and respond to questions and requests for resources. The critical feature of this host is that he or she is welcoming, enjoys socializing, and has some experience interacting with people who have ADRD. Other staff or volunteers often support café set-up, sign-in, socializing and oversight. Most memory cafés also include (or have ready access to) at least one professional—usually a nurse, social worker, or counselor—who can speak with care partners or persons with ADRD about dementia-related issues and concerns should they arise, and about caregiving resources and supports (this is often the role of professional staff within county offices for the aging). Other common characteristics of memory cafés are summarized in Section II.

During the COVID-19 pandemic, adaptations are being made in the delivery of memory cafés due to social distancing requirements and other safety precautions for older adults, many of whom are particularly vulnerable to infection. Some memory cafés have ceased operating during the pandemic while others have moved to outdoor or online operations. Implications of moving to online operations include changes in attendee profiles, special attention to technology needs and training, additional communication and recruitment to ensure participants are aware of modified services, and expansion opportunities with other at-risk populations who aren’t typical memory café guests.

Memory cafés are proliferating around the world because they have been shown to have beneficial effects and impacts for participants. Section III summarizes the many benefits of memory cafés for persons with ADRD and their caregivers identified in the literature and by field experts. Positive effects of memory cafés include the following (adapted from Massachusetts Memory Café Toolkit):

- Memory cafés normalize people living with ADRD and their care partners/caregivers
- Memory cafés provide peer support with others who can empathize
- Cafés allow care partners to develop social networks and reduce social isolation
- Care partners view memory cafés as a kind of respite and an opportunity to enjoy themselves socially (together with the person who has dementia)
- They provide a space where ADRD is not “in the room” and where people at any stage of disease progression are welcome
- Cafés act as a cost-effective entry point for needed resources and way to support both the person with ADRD and the care partner
- Cafés foster participation in social activities and creative and cognitive stimulation that promote improved memory function in persons with ADRD. Many cafés involve music, creative and performing arts because these draw upon aspects of cognitive functioning that are affected last and least by dementia.
- Cafés offer access to education, information, support, and services for persons with ADRD and their care partners as the diseases progresses.

Summarized in Section III and in the Appendix, Tables 2 and 4, research literature on the demonstrated benefits of creative and performing arts as both therapeutic intervention and a form

of socialization and relaxation speak to the potential benefits of memory café activities for those with ADRD and their caregivers. Interventions such as painting, singing, and dancing have been shown to have a significant effect on the emotional and behavioral health of those with ADRD—along with their caregivers—as well as improving overall quality of life. Using arts-based programming in memory cafés, though already widely adopted, is perhaps worth considering more intentionally, particularly so that program coordinators and funders might cultivate arts resources from the community in café design.

There is no single model for a memory café that is preferable over another. (Memory cafés are not intellectual property; the term cannot be copyrighted and the concept cannot be patented.) Beyond its core mission of offering a safe and inclusive space for people with ADRD and their care partners to socialize, a memory café's specific activities, structure, and services will vary from café to café. Section IV summarizes tips and strategies for operating a memory café. These guidelines are an amalgam of best practices and expert opinions derived from published café toolkits and experience. Included in the Appendix is a summary of available toolkits and other operations resources for those looking to fund or create a memory café.

Today, nearly 900 memory cafés exist in all 50 U.S. states. As of September 2020, the Memory Café Directory ([an online repository](#) that catalogues memory cafés worldwide) reports the states with the most memory cafés are: Wisconsin (139 cafés), Massachusetts (130), Illinois (40), Washington (37), Texas (37), and Minnesota (36). Section V examines the rapid growth and characteristics of the memory café movement in best practice states like Wisconsin and Massachusetts. Memory café activity in New York and Michigan is also summarized. Variants of the memory café model are also addressed, for example [Alz Meet Ups](#), an Alzheimer's Association-sponsored program designed for individuals who are in the early stages of ADRD.

In Section VI, we consider the core characteristics of memory cafés and analyze how they might apply to social isolation more generally. Given their potential role in advancing age and dementia friendly communities, and the low-key, drop-in, voluntary services that they provide, memory cafés could effectively attract other at-risk populations that would likely experience similar health and psychosocial benefits as persons with ADRD, such as persons with early-stage ADRD, socially isolated older adults, isolated older adults in rural areas, and caregivers. These at-risk groups present opportunities for memory café growth and adaptation.

Services offered by memory cafés could provide benefits to a wider audience of older adults, producing an amelioration of the negative effects caused by social isolation (including the onset of ADRD), along with a larger, broad-based destigmatizing not only of ADRD but also the experience of aging as a whole. Adaptions in café program delivery, marketing, or other attributes – such as offering online memory cafés, marketing to non-ADRD audiences, and transportation support – may broaden the appeal of memory cafés to other older adults and caregivers.

Strategies that support memory café replication and sustainability are addressed in Section VII. Analysis of the growth of memory cafés in states where they have flourished suggests that local funding, partnerships with government agencies, favorable state and local policies, local individual champions, resources and technical assistance from memory café incubators, and media coverage are all effective drivers in helping cafés expand and thrive. Typically, it is a confluence of these factors that creates the most favorable conditions for memory café growth and sustainability.

Massachusetts' and Wisconsin's memory café resources and infrastructure illustrate this point (see Section VII).

Finally, included in the Appendix of this report is information useful for both funders in the memory café space as well as individuals and organizations who are seeking to create memory cafés. Tables 1-4 in the Appendix include research literature and reports about: memory café operations and evaluations of their impact on participants, the impact of performing arts on ADRD, social isolation, and interventions related to ADRD and social isolation. Table 5 in the Appendix is a repository of directories, toolkits, and other resources related to memory café design, operations, and supports.

## I. Introduction

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In July 2020, the Ralph C. Wilson Jr. Foundation and Health Foundation for Western and Central New York retained The Philanthropic Initiative to conduct an environmental scan of memory café activity, impact, and best practice. The funders seek information on the memory café model to help inform the field and potential next steps for expanding memory cafés in western and central New York and southeast Michigan.

Memory cafés are designed to offer a safe, comfortable, and stimulating gathering space typically for persons with Alzheimer's disease and related dementias (ADRD) and their caregivers. The model is a strategy most frequently used to promote social support and connection, socialization, health, and wellbeing among attendees who are usually older adults. The growth of memory cafés throughout the United States and in other countries speaks both to the critical need they meet and the unique supports they provide.

The primary goals of this environmental scan are to:

- Define and describe memory cafés including their core characteristics and geographic presence
- Summarize the demonstrated benefits of memory cafés for participants and caregivers (as identified in the literature)
- Articulate the effective components and best practices of cafés and offer practical guidelines and tools for their implementation
- Identify drivers of successful memory café expansion

This environmental scan also explores the following questions:

- How do memory café activities and growth compare regionally, particularly in New York and Michigan, and in states where there has been considerable uptake, such as Massachusetts and Wisconsin?
- What are key memory café operating models and how are they sustained?
  - What are common funding sources?
  - What is the involvement of state and other governmental agencies (such as Area Agencies on Aging) in supporting and promoting cafés?
- How might memory cafés be used to support or benefit older adult populations other than persons with ADRD and their caregivers?

Finally, we address the effects of the COVID-19 pandemic on memory cafes, including the emergence of technology-based strategies that allow for virtual cafe models, and how these models might have broader applications with different adult populations.

This scan examines and summarizes publicly available information about memory cafes. Research was conducted primarily online, including web-based research and online literature review. Expert opinion was sought out to shed light on memory café areas where published information is scarce.

## II. Memory Cafés for Persons with Alzheimer's/ Dementia and their Caregivers

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### ADRD Overview

Dementia is an overall term for a particular group of symptoms including difficulties with memory, language, problem-solving and other cognitive skills that interfere with a person's ability to perform everyday activities. Among the many causes of dementia, Alzheimer's disease is the most common, accounting for 60 to 80 percent of all cases.<sup>1</sup>

According to the Alzheimer's Association, 5.8 million people, or 1 in every 10 people age 65 and older, are currently living with a diagnosis of ADRD in the United States; that number is expected to increase to 14 million by 2050.<sup>2</sup> As the size of US population over age 65 continues to grow, both the number of persons living with ADRD and the proportion of Americans living with ADRD will increase, too.<sup>3</sup> Black/African American and Latinx populations have disproportionately higher risk of developing dementia than white populations.<sup>4</sup> Women are more likely than men to develop ADRD, but this is largely because women live longer than men on average.<sup>5</sup> Increased age is the greatest risk factor for ADRD.<sup>6</sup>

### What is a Memory Café?

A memory café is a model or strategy most frequently used to promote social support and connection, socialization, health, and wellbeing for persons with ADRD and their caregivers in a welcoming environment. Memory cafés offer a supportive, comfortable, and stimulating gathering space for all ADRD participants at any stage of disease progression, including those for whom ADRD is an underlying condition. Cafés are a safe space for regular social interaction where participants and their caregivers can talk with others who have similar lived experiences, mitigate limitations and instead focus on strengths, enjoy one another's company, explore creativity, and learn something new. Memory cafés provide a setting to listen to music, sing, play games, engage in the arts, socialize, and share community with those living with memory loss and other cognitive challenges. Many cafés request that guests bring their care partner, whether it is a friend, spouse, other relative, or a paid caregiver.

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<sup>1</sup> "What Is Alzheimer's?" Alzheimer's Disease and Dementia, accessed September 21, 2020, <https://www.alz.org/alzheimers-dementia/what-is-alzheimers>.

<sup>2</sup> "2020 Alzheimer's Disease Facts and Figures: On the Front Lines: Primary Care Physicians and Alzheimer's Care in America" Alzheimer's Association, Accessed September 21, 2020, [www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf](http://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf).

<sup>3</sup> *Ibid.*

<sup>4</sup> *Ibid.*

<sup>5</sup> *Ibid.*

<sup>6</sup> *Ibid.*

A clinical ADRD diagnosis is not required to attend a memory café. In the United States, ADRD is typically not a focus of organized group discussion at memory cafés since medical concerns or memory-related topics are usually not part of programming. Memory cafés are open to all older adults with or without current memory concerns. This way, individuals who have not yet been diagnosed or are not comfortable with their diagnosis feel welcome. Still, memory cafés are designed to engage attendees in cognitive activities in order to improve memory and brain health. The goal is to keep attendees mentally and socially active, which research shows is protective of brain health (see more about this evidence in “Section III. Benefits of Memory Cafés”).

Memory cafés take place in many different community venues, including libraries, houses of worship, local restaurants, performing arts and other community centers, nature centers, senior centers, assisted living centers, and other locations. Memory cafés usually meet for two hours once or twice a month and operate on a drop-in basis. Regardless of where they are held, memory cafés share a commitment to offering hospitality, refreshments, and interesting and engaging programs. While information about ADRD as well as community resources and services (often through brochures from organizations like the Alzheimer’s Association) are available for those who seek it, cafés are primarily intended to provide a break from focusing on disease and disability. They strive for an atmosphere that is more like a coffee house or a neighborhood party than a clinical program. A well-designed café helps participants living with ADRD to feel safe, confident, and successful. This in turn can provide a respite experience for caregivers, who are able to relax, chat with others, and enjoy having a good time together with their loved one or care partner with ADRD.

## Memory Café Definitions and Terminology

Depending on the specific region or community, different terminologies are used for memory cafés. For example, some of these spaces are referred to as Alzheimer’s Cafés, Memory Care Cafés, or Neighborhood Memory Cafés. In addition to using different names, some practitioners differentiate a European model from a U.S. model. The former focuses on topics directly related to various diagnoses of dementia and caring for an individual with dementia—for example, tools to promote more effective communication or environmental adaptation to make homes feel safer—while the latter focuses largely on providing a respite from thinking about ADRD through relaxation, recreation-focused activities, and social support.<sup>7</sup>

Different terminology is also used for those who attend memory cafés. Some café staff refer to their “participants” while others talk about their “guests” or “clients.” Regardless of the language used, memory café facilitators and volunteers are trained not to refer to participants as “patients” or “dementia patients,” or to use other terms that diminish the full personhood of the individual living with memory loss, confusion, and other cognitive problems.

Similarly, some communities that focus on aging populations refer to those who provide care to individuals with ADRD as “care partners” rather than “caregivers.” A caregiver is typically defined as someone who provides care for a person who is unable to care for themselves or needs some degree of help with self-care, which for some connotes a one-way relationship between two people, with one person giving and the other passively receiving. For those who view care as a more

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<sup>7</sup> The Alzheimer’s Café Model: A Guide to Getting Started in Your Community,” a presentation developed by the Dementia Action Collaborative of Washington State, [https://depts.washington.edu/mbwc/content/page-files/DAC\\_Alz\\_Cafe\\_Webinar\\_-\\_Jan\\_24,\\_2018.pdf](https://depts.washington.edu/mbwc/content/page-files/DAC_Alz_Cafe_Webinar_-_Jan_24,_2018.pdf).



collaborative or even reciprocal activity, the term care partner may better describe this balance.<sup>8</sup> Where carers see themselves on a continuum from caregiver to care partner is largely a matter of personal experience and perspective, and how they define their role a matter of personal choice. For this reason, we use the terms *caregiver* and *care partner* interchangeably throughout this report.

Memory cafés should be differentiated from traditional respite programs, planned or emergency temporary care provided for caregivers/care partners. According to the National Institute on Aging, respite care provides short-term relief for primary (family or other unpaid) caregivers.<sup>9</sup> It can be arranged for just an afternoon or for several days or weeks. Care can be provided at home, in a healthcare facility, or at an adult day center. Care partners might use this time for practical purposes (e.g., shopping, cleaning, running errands, etc.) or for reasons related to emotional or mental health. Caregivers do not “drop off” their loved one at a memory café. Rather, the caregiver and caree have opportunities to enjoy activities together. Because memory cafés incorporate care partners along with participants into their services, they are not considered social adult day programs or other traditional respite programs, even if they might offer a form of respite; the social and creative time they offer can function as a kind of “safe haven” for caregiver respite. In this way, memory cafés support a broader definition of respite. Memory cafés are also not typically structured as traditional support programs, although participants often receive and offer one another informal support.

## History of Memory Cafés

The first memory café was launched in 1997 by Dutch clinical psychologist Dr. Bère Miesen in Leiden, Holland. Miesen’s goal with the café was to break the stigma associated with various forms of dementia. The memory café clearly addressed a need. Over the following decades, the model spread as a grassroots movement across many countries including the United States, Europe, Canada, and Australia. (Memory cafés are not intellectual property; as a result, the term cannot be copyrighted and the concept cannot be patented.) In 2008, Dr. Jytte Lokvig started the first United States-based memory café in Santa Fe, New Mexico. That same year, Lori La Bey started Arthur’s Memory Café in Roseville, Minnesota. Since 2008, grass roots efforts have prompted the continued proliferation of memory cafés throughout the United States.<sup>10</sup>

Since 1997, two memory café models have evolved:

- The European Model features presentations and information on Alzheimer’s issues combined with a social hour. Some memory cafés in this model offer memory assessment services. Care partners are offered ADRD-related clinical consultation and support.
- The American Model focuses on socialization and entertainment or recreation activities as a form of respite. Participants, both the person with memory loss and the care partner, enjoy a social time with potential activities. Staff and/or volunteers are there to create a supportive environment.

Some memory cafés in the United States provide information about ADRD as many European cafés do, but most concentrate on socializing and respite from the disease. Many cafés in countries where

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<sup>8</sup> Linda Shin, “Care Partner’s Guide: Care Partner versus Caregiver,” HOPES Huntington’s Disease Information, April 13, 2018, <https://hopes.stanford.edu/care-partners-guide-care-partner-versus-caregiver/>.

<sup>9</sup> “Caregiving,” National Institute on Aging, U.S. Department of Health and Human Services, Accessed September 21, 2020, [www.nia.nih.gov/health/caregiving](http://www.nia.nih.gov/health/caregiving).

<sup>10</sup> The Alzheimer’s Café Model: A Guide to Getting Started in Your Community,” a presentation developed by the Dementia Action Collaborative of Washington State, [https://depts.washington.edu/mbwc/content/page-files/DAC\\_Alz\\_Cafe\\_Webinar\\_-\\_Jan\\_24\\_2018.pdf](https://depts.washington.edu/mbwc/content/page-files/DAC_Alz_Cafe_Webinar_-_Jan_24_2018.pdf).

there is a public health system include a public health nurse and may even offer a diagnostic screening right at the café.

## Characteristics of a Memory Café – The American Model

While there are not strict parameters for what a memory café must or must not include to be considered a memory café, there are some characteristics that are common among many cafés. Memory cafés are typically staffed by an individual (one consistent person) who acts as host or facilitator and who can offer guidance and respond to questions and requests for resources. This person might be paid or be a volunteer. Important features of this host are that he or she is welcoming, enjoys socializing, and has some experience interacting with people who have ADRD. Other staff or volunteers often support café set-up, sign-in, socializing and oversight.

Most memory cafés also include (or have ready access to) at least one professional or trained volunteer—usually a nurse, social worker, or counselor—who can speak with care partners or persons with ADRD about dementia-related issues and concerns should they arise and about caregiving or resources for caregiving support. These individuals may be volunteers who are retired or who have extra time in their work schedules; or they may be supported by their employers to attend or be on call (for example, this is often a role for professional staff in county or regional offices for the aging).

Other typical, key characteristics of a memory café include the following:

- **Location:** Cafés may take place in a variety of (*easily accessible*) venues in the community.
- **Timing:** Cafés normally run 1.5 to 2 hours, usually once per month. Memory cafés operate on a drop-in basis for new or returning participants with no pre-registration required. Cafés occur at different days of the week/times as determined by café organizers (ideally with attendee input).
- **Schedule:** Most cafés begin with relaxed socializing before shifting to a planned activity and ending with more social time.
- **Activities:** Beyond socializing, memory cafés may also offer various activities for participants including arts and crafts, historical and cultural projects, and physical exercise (e.g., a garden walk, a trip to a nature center or public park, etc.). Each memory café determines its own activities. Some cafés incorporate interactive activities like sing-a-longs and storytelling. Other activities might be centered around holiday or seasonal themes. Many cafés report that facilitated interaction is critical to the success of any planned activity. Many also report that guests primarily request socializing or participating in simple activities that café coordinators can facilitate themselves, such as listening to music, sharing photos, holiday recipes, etc.
- **Role of Caregivers:** Many cafés request that participants bring their care partner, whether it is a friend, partner, relative, or professional caregiver. One reason: participants may require personal care or assistance participating in the café. By design, caregivers participate in memory café activities together with participants or they can interact with other care partners, staff, or volunteers in attendance. Importantly, memory cafés offer and provide a respite experience for care partners, who are able to relax, socialize, take a break, and learn about community resources.
- **Creative & Performing Arts:** Many cafés involve the creative and performing arts, such as music, dance, poetry, visual arts, and arts education. Research has shown that music and

art can bring back a connection to the past, stimulating memories and the ability to reminisce (see Section III. “Benefits of Memory Cafés”). Another benefit of creative arts is that guests can participate and be challenged no matter their cognitive abilities since there are no wrong answers. Also, engaging in creative arts helps normalize ADRD and level the playing field between participants and their care partners.

- **Supplies:** In addition to any supplies that are used for activities (e.g., materials for arts and crafts, A/V equipment, etc.), refreshments are typically provided for participants and their caregivers, along with brochures or educational materials that typically relate to community resources, other activities, and services for people living with ADRD and their caregivers.
- **Marketing:** Memory cafés are typically publicized by making connections with senior centers, local Alzheimer’s associations, assisted living facilities, home care agencies, Area Agencies on Aging, and other agencies serving older adults in the community. This outreach might also be used to recruit staff, volunteers, or referrals to other professional services or community-based support for persons with ADRD and their care partners.
- **Community Support:** Memory café organizers often successfully cultivate donations of space, arts/entertainment talent and facilitation support, other professional services, and food and supplies from local businesses. Local health and social service agencies frequently help memory cafés operate in communities.

Overall, a well-designed café offers a space for participants with ADRD to feel safe and connected. At memory café gatherings, people do not need to worry about the social stigma that is often associated with dementia. The atmosphere at cafés is normalizing with the intent to restore a sense of “normalcy” for both the person with the diagnosis and their care partner.

*“The best cafés are those where you can’t tell who has the diagnosis and who doesn’t.”*  
-Jytte Lokvig, memory café pioneer in the U.S.

### *What a Memory Café Is and Is Not - Voices from the Field*

The Massachusetts-based Jewish Family & Children’s Services’ [Percolator Memory Café Network](#) developed in 2016 a Memory Café Toolkit, a resource to help others interested in launching a memory café. Included in the Toolkit is a list of norms and standards entitled, “[What a Memory Café Is and Isn’t](#).” According to this guide: “While no one has the authority to enforce these standards, and cafés should be tailored to unique needs of their community, coordinators of new cafés are urged to give the following standards careful consideration.”

Building on the key characteristics of memory cafés (outlined above), the Massachusetts Memory Café Toolkit reports what a memory cafe is:

- A meeting place for individuals living with changes in their thinking or memory, mild cognitive impairment or dementia due to ADRD. It’s a place to relax, have fun, and meet others. A diagnosis of dementia is not required to attend.
- A meeting place for care partners, who can enjoy a change of scene and routine, meet other care partners to exchange ideas and learn about resources, and experience respite and renewal in their relationship with the person in their life who has ADRD.
- Structured to support and engage individuals with a range of cognitive needs, including those with cognitive changes, and family, friends, and other care partners.

- Managed by community advocates and/or volunteers with experience or training in working with individuals with cognitive impairment.
- A time to focus on socializing, exploration and respite from disease and disability.
- An opportunity to learn where to find support and services for those who are looking for this type of information.
- Free of charge or open to those who cannot pay to attend.
- A program that strives for inclusion. This includes physical accessibility, respect for and inclusiveness of different cultures, and freedom from stigma.
- Unique in character, based on the interests and style of the community where it is located and/or the individuals whom it serves.

Conversely, the Toolkit reports what a memory café is not:

- A workshop, seminar or lecture about dementia
- A facilitated support group
- A drop-off respite program
- Primarily a marketing opportunity for a commercial enterprise.

*"There is no set way (single model) of doing a memory café although the commitment to hospitality and inclusion lies at the heart of the best practices of all memory cafés."*

*-Susan McFadden, PhD, Professor Emerita, University of Wisconsin Oshkosh*

### *Memory Cafés During the COVID-19 Pandemic*

Memory café practitioners report that during the COVID-19 pandemic, adaptations are being made in the delivery of cafés due to social distancing requirements and other safety precautions for older adults, many of whom are particularly vulnerable to infection. Some memory cafés have ceased operating during the pandemic while others have moved to outdoor or online operations (via Zoom). Implications of moving to online operations include:

- Changes in Attendance – In order to participate, care partners/participants must have computer and internet access and capability.
- Expanded Recruitment – While participant and caregiver recruitment are always part of the memory café operations landscape, it is even more essential during the pandemic so that potential guests are aware of how and when they can access an online memory café experience. What's more, communications must be modified so that existing café participants are aware of new schedules and services.
- Opportunity for Memory Café Expansion – Without a physical café location, barriers such as distance, travel time, or lack of transportation can be overcome and accommodated with virtual cafés. Online memory cafés can also recruit participants from broader geographic areas, including rural settings (see "Section VI. Memory Café Applications for Other Older Adult Populations").

## III. Benefits of Memory Cafés

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### Health of Care Partners and the Impact of ADRD Caregiving

In their 2020 Alzheimer’s Disease Facts and Figures report, the Alzheimer’s Association reported 83 percent of the help provided to older adults comes from family, friends, or unpaid caregivers.<sup>11</sup> More than 75 percent of caregivers are female, with an average age of 49 years. Thirty-four percent of caregivers are 65 or older.<sup>12</sup> The profile of the average caregiver in America is a 49-year-old woman who works outside the home and still provides 20 hours of unpaid care per week to her mother.<sup>13</sup> In fact, more than 16 million caregivers provide 18.6 billion hours of unpaid care to persons with ADRD each year, valued at \$244 billion.<sup>14</sup> Clearly, an ADRD diagnosis impacts not only the individual, but their care partners and other family members, as well. While caregivers generally report positive feelings about the care they provide, they also frequently report higher levels of stress, particularly in terms of their emotional and social wellbeing. The same report offers important context about the overall health of caregivers:

- 59 percent of family caregivers of people with ADRD rated the emotional stress of caregiving to be high or very high.
- A meta-analysis reported that caregivers of people with ADRD were significantly more likely to experience depression and anxiety than non-caregivers or caregivers of individuals with schizophrenia or stroke.
- Caregivers of individuals with ADRD report more subjective cognitive challenges—such as problems with memory and greater declines in cognition over time—than non-caregivers.
- 29 percent of caregivers of people with ADRD report that providing care results in high physical strain compared with 17 percent of non-ADRD caregivers.
- 74 percent of caregivers of people with ADRD report being “somewhat concerned” to “very concerned” about maintaining their own health.

Overall, the stress associated with ADRD caregiving has been associated with an increased incidence of hypertension, high levels of stress hormones, impaired immune function, and coronary heart disease among caregivers.<sup>15</sup>

### The Interconnectedness of ADRD, Social Isolation, and Loneliness

Unfortunately, ADRD continues to be a misunderstood disease and people with the diagnosis often experience a contraction of their social groups as a number of family members and long-time friends pull away. As a result, people living with ADRD, as well as their care partners, often become socially isolated. Social isolation can be defined as the “[structural] absence of social interactions, contacts, and relationships with family and friends, with neighbors on an individual level, and with “society at

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<sup>11</sup> “2020 Alzheimer’s Disease Facts and Figures: On the Front Lines: Primary Care Physicians and Alzheimer’s Care in America” Alzheimer’s Association, Accessed September 21, 2020, [www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf](http://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf).

<sup>12</sup> “Caregiver Statistics: Demographics,” Family Caregiver Alliance, April 17, 2019. [www.caregiver.org/caregiver-statistics-demographics](http://www.caregiver.org/caregiver-statistics-demographics).

<sup>13</sup> “Which Type of Caregiver Are You?: Where You Live Matters,” ASHA, June 24, 2020. [www.wherewelivematters.org/which-type-of-caregiver-are-you/](http://www.wherewelivematters.org/which-type-of-caregiver-are-you/).

<sup>14</sup> “2020 Alzheimer’s Disease Facts and Figures: On the Front Lines: Primary Care Physicians and Alzheimer’s Care in America” Alzheimer’s Association, Accessed September 21, 2020, [www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf](http://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf).

<sup>15</sup> *Ibid.*

large” on a broader level.<sup>16</sup> This is due to the increasing difficulty of engaging in everyday activities, compounded by the stigma that makes people with ADRD and their caregivers feel unwelcome or embarrassed when symptoms occur in public situations. The unfortunate result is isolation, which is a driver of other health risks, including the rapid worsening of dementia. Social isolation has been associated with a number of adverse health consequences including depression, impaired immunity, poor cardiovascular function and, most perniciously for those living with ADRD and other older populations, accelerated cognitive decline.<sup>17</sup>

While not a clinically recognized disease, loneliness—or the subjective perception of being alone, isolated, or deficient in social relations—functions similarly to social isolation.<sup>18</sup> Researchers have found that loneliness is associated with a 40 percent increase in a person’s risk of dementia.<sup>19</sup> Other studies have found that engaging older adults in community and social groups can lead to positive mental health effects and reduce feelings of loneliness. (See “Section VI. Memory café Applications for Other Older Adult Populations” for further discussion).

The increasing difficulty of engaging in everyday activities, compounded by the stigma that makes people feel unwelcome or embarrassed when symptoms occur in public situations, may lead to people with ADRD or their care partners choosing to isolate. Fear and stigma go hand in hand, creating a social dynamic in which many are afraid to acknowledge their symptoms and seek medical evaluation, thus exacerbating their health challenges. In a survey of 2,500 people living with dementia in 54 countries, the [2012 World Alzheimer’s Report](#) found:

- 60 percent of respondents have “been avoided or treated differently because of their diagnosis.”
- 40 percent of respondents have been excluded from everyday activities.
- Almost 25 percent concealed their diagnosis from family or friends, due to fear of being stigmatized.

## Research on the Impact of Memory Cafés: A Summary of the Literature

Published research on the memory café literature in the United States is scant. One reason for this is the sheer abundance and diversity of memory café types—there is no single model or approach for consistent, rigorous analysis. Still, available research on memory cafés, particularly in other parts of the world, have shown real benefits. Investigators in the UK interviewed care partners from a number of different cafés and found four themes emerged:

- Care partners viewed memory cafés as a kind of respite and an opportunity to enjoy themselves socially
- Memory cafés normalized people living with ADRD
- Memory cafés provided peer support

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<sup>16</sup> “Social Isolation Among Older Individuals: The Relationship to Mortality and Morbidity,” The Second Fifty Years: Promoting Health and Preventing Disability, U.S. National Library of Medicine, January 1, 1992, [www.ncbi.nlm.nih.gov/books/NBK235604/](http://www.ncbi.nlm.nih.gov/books/NBK235604/).

<sup>17</sup> “Loneliness and Social Isolation Linked to Serious Health Conditions,” Centers for Disease Control and Prevention, May 26, 2020, [www.cdc.gov/aging/publications/features/lonely-older-adults.html](http://www.cdc.gov/aging/publications/features/lonely-older-adults.html).

<sup>18</sup> “Social Isolation, Loneliness in Older People Pose Health Risks,” National Institute on Aging (U.S. Department of Health and Human Services), accessed September 21, 2020, [www.nia.nih.gov/news/social-isolation-loneliness-older-people-pose-health-risks](http://www.nia.nih.gov/news/social-isolation-loneliness-older-people-pose-health-risks).

<sup>19</sup> Angelina R Sutin, PhD, Yannick Stephan, PhD, Martina Luchetti, PhD, Antonio Terracciano, PhD, Loneliness and Risk of Dementia, *The Journals of Gerontology: Series B*, Volume 75, Issue 7 (September 2020), Pages 1414–1422, <https://doi.org/10.1093/geronb/gby112>.

- Cafés allowed care partners to develop social networks and reduce social isolation.<sup>20</sup>

Interestingly, these findings were found to be independent of the individual needs of the care partner and the way in which the specific memory café was organized, which supports the notion that, despite the diversity of experiences and services that memory cafés might provide, participants derive value from them predominantly because they are a space to feel safe, connected and supported. In addition to the benefits of social supports and connectedness derived from memory café participation (summarized below and in the Appendix, Table 1), many cafes also engage participants and caregivers in the creative and performing arts. Summarized below (and in the Appendix, Table 2) is evidence suggesting that creative and performing arts activities also provide therapeutic benefits and respite opportunity for café participants and caregivers.

### *Literature on the Benefits of Memory Cafes*

In an evaluation of a memory café in Australia, researchers found that enjoyment, social inclusion and peer support, and the ability to access information were the most common reasons for participants to attend a memory café.<sup>21</sup> In fact, the majority of the participants had regularly attended the café for many years and expressed hope they would be able to continue attending if they or the person they accompanied had to be placed in residential care. Another study from Japan—which has seen dramatic growth in memory cafés from 50 in 2012 to 4,267 in 2017—looked at memory café participants and found there was a strong correlation between the number of participants at a café and the positive impact perceived by people with ADRD and their care partners; in other words, the more people who attended, the better the effects.<sup>22</sup> What’s more, these memory cafés saw a sizable number of participants that identified as community members who were concerned about developing ADRD in the future rather than actually being presently diagnosed with ADRD, suggesting a model with a more expansive approach in its outreach. (The use of memory cafés for other populations beyond those with ADRD and their caregivers is explored further in Section VI.)

Memory cafés have also been connected to the ability of care partners to self-protect and cope in the face of crisis. In looking at the biggest predictors of memory café attendance, another study from the UK showed that care partners who attended memory cafés reported a greater sense of resilience and subjective wellbeing than care partners who didn’t attend.<sup>23</sup> (Interestingly, female care partners and care partners with fewer years of formal education were more like to attend a memory café compared to their male counterparts and care partners who had completed more years of education.)

Finally, research has shown that social activities that are common to memory cafés may help treat particular symptoms associated with ADRD and improve the quality of life for those with the disease. For example, a study by the *Annals of Internal Medicine* showed that massage and music therapy are effective at reducing agitation and aggression among people with ADRD.<sup>24</sup> Relatedly,

<sup>20</sup> N. Greenwood, R. Smith, F. Akhtar, *et al.*, “A qualitative study of carers’ experiences of dementia cafés: a place to feel supported and be yourself,” *BMC Geriatrics*, 17, 164 (2017). <https://doi.org/10.1186/s12877-017-0559-4>.

<sup>21</sup> Briony Dow, Betty Haralambous, Courtney Hempton, Susan Hunt, and Diane Calleja, “Evaluation of Alzheimer’s Australia Vic Memory Lane Cafés,” *International Psychogeriatrics* 23, no. 2 (2011): 246–55, <https://doi.org/10.1017/S1041610210001560>.

<sup>22</sup> “Dementia Cafés That Balance Programs, Guests Can Have Positive Impact,” AMDA, December 10, 2019, <https://paltc.org/newsroom/dementia-cafe/C3%A9s-balance-programs-guests-can-have-positive-impact>.

<sup>23</sup> S.M. Jones, A. Killlett, E. Mioshi, “What Factors Predict Family Caregivers’ Attendance at Dementia Cafés?,” *Journal of Alzheimer’s Disease*, 64(4):1 (2018), 337-1345, <https://pubmed.ncbi.nlm.nih.gov/29991136/>.

<sup>24</sup> Jennifer A. Watt *et al.*, “Comparative Efficacy of Interventions for Aggressive and Agitated Behaviors in Dementia,” *Annals of Internal Medicine*, accessed September 21, 2020, <https://www.acpjournals.org/doi/10.7326/M19-0993>.  
<https://www.acpjournals.org/doi/10.7326/M19-0993>

music-based interventions have demonstrated a strong association between music and personal identity and relationship-building for people at all stages of ADRD.<sup>25</sup> Other research suggests that memory and cognitive function may be improved with stronger social interactions.<sup>26</sup> Consequently, the memory café experience, whether through specific activities like singing or general time spent socializing, may have an impact on how ADRD might physically or cognitively symptomize.

See the Appendix Table 1 for a summary of published studies and information sources on memory café benefits for people with ADRD and their caregivers.

### *Literature on the Benefits of Creative and Performing Arts for Persons with ADRD*

The lack of academic or clinical research into the positive effects of memory cafés on persons with ADRD extends to investigations on the use of creative and performing arts activities within memory cafés. Still, given how central this kind of programming is to typical memory café offerings, special attention might be paid to their use more broadly, specifically in examining their known benefits for individuals with ADRD. For example, a Chinese “folk recreation program” in which participants engaged in folk art-based activities including crafts, drawing, and coloring yielded noticeable improvements in cognitive functioning (e.g., orientation, attention, calculation, recall, etc.).<sup>27</sup> A review of music therapies found promising (if inconclusive) results in the use of both active (singing and playing musical instruments) and passive (listening) music techniques for decreasing depression, anxiety, and agitation among those with ADRD.<sup>28</sup> In fact, a meta-analysis comparing interventions for treating aggression and agitation in adults with ADRD found that non-pharmacological treatments like music combined with touch therapy were more effective than pharmacologic treatments.<sup>29</sup>

Even if activities don’t demonstrate a change in the cognitive health of persons with ADRD, they may have other positive effects worth exploring. A study in England measured quality of life outcomes of a “singing together group” comprised of musicians, people with ADRD, and their caregivers. Researchers found that these activities centered around collective singing had a positive impact on how individuals with ADRD perceived their personal relationships, overall mood and wellbeing, and acceptance of their diagnosis.<sup>30</sup> The *American Journal of Alzheimer’s Disease & Other Dementias* published a study that examined the use of reminiscent music and movement therapy—using natural movements as a form of unstructured dancing—among persons with ADRD. The investigators concluded that, while not observed uniformly, most participants indicated an increase in quality of life scores centered around positive memory recollection, social interactions, and overall enjoyment.<sup>31</sup> Another observation of a hands-on art-making activity for individuals with ADRD

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<sup>25</sup> O. McDermott, M. Orrell, HM Ridder, “The Importance of Music for People with Dementia: the Perspectives of People with Dementia, Family Carers, Staff and Music Therapists,” *Aging & mental health* (U.S. National Library of Medicine), accessed September 21, 2020, <https://pubmed.ncbi.nlm.nih.gov/24410398/>.

<sup>26</sup> Y. Hu, X. Lei, J.P. Smith, *et al.*, “Effects of Social Activities on Cognitive Functions: Evidence from CHARLS,” National Research Council (US) Panel on Policy Research and Data Needs to Meet the Challenge of Aging in Asia, edited by J.P. Smith and M. Majmundar, *Aging in Asia: Findings From New and Emerging Data Initiatives*, Washington, DC: National Academies Press, (2012): 12; <https://www.ncbi.nlm.nih.gov/books/NBK109224/>.

<sup>27</sup> Dong-mei Li, and Xiao-xue Li, “The Effect of Folk Recreation Program in Improving Symptoms: A Study of Chinese Elder Dementia Patients,” *International Journal of Geriatric Psychiatry* 32, no. 8 (2017), 901-08, <https://doi.org/10.1002/gps.4543>.

<sup>28</sup> R. Blackburn, and T. Bradshaw, “Music Therapy for Service Users with Dementia: A Critical Review of the Literature,” *Journal of Psychiatric and Mental Health Nursing* 21, no. 10 (2014): 879-88, <https://onlinelibrary.wiley.com/doi/abs/10.1111/jpm.12165>.

<sup>29</sup> Jennifer A. Watt, Zahra Goodarzi, *et al.*, “Comparative Efficacy of Interventions for Aggressive and Agitated Behaviors in Dementia: A Systematic Review and Network Meta-analysis,” *Annals of Internal Medicine* 171, no. 9 (2019): 633, <https://doi.org/10.7326/M19-0993>.

<sup>30</sup> Sara Osman, Tischler Eldirdir, *et al.*, “Singing for the Brain: A Qualitative Study Exploring the Health and Well-being Benefits of Singing for People with Dementia and Their Carers,” *Dementia* (London, England) 15, no. 6, 2016, 1326-339, <https://europepmc.org/article/med/24336767>.

<sup>31</sup> Ting Choo, Yoram Barak, and Ali East, “The Effects of Intuitive Movement Reembodiment on the Quality of Life of Older Adults With Dementia: A Pilot Study,” *American Journal of Alzheimer’s Disease & Other Dementias*, (January 2020), <https://doi.org/10.1177/1533317519860331>.



found that participants were better able to maintain interest and engagement without becoming sad, anxious, or angry.<sup>32</sup> Additional research has uncovered similar results with regards to the overall positive effects of arts programming for persons with ADRD: playing of personally meaningful music and engagement led by trained music therapists;<sup>33</sup> an art-viewing and art-making class led by community arts partners;<sup>34</sup> and the Alzheimer's Association's "[Memories in the Making](#)" art program.<sup>35</sup>

While the potential benefits of memory café creative and performing arts activities have not been formally studied, the use of these therapies as a tool for those with ADRD is evident. Using arts-based programming in memory cafés, though already widely adopted, is perhaps worth considering more intentionally, especially as program coordinators and funders cultivate resources from the community in café design (see the Appendix, Table 2 for a summary of published evidence on the benefits of creative and performing arts for people with ADRD).

## Benefits of Memory Cafés: Voices from the Field

The proliferation of memory cafés reflects an increased belief about the beneficial effects and impacts for persons with ADRD and their care partners. Practitioners and field experts identify positive effects of memory cafés, including the following (primary source is the Massachusetts Memory Café Toolkit):

- Memory cafés normalize people living with ADRD and their care partners
- Memory cafés provide peer support with others who can empathize. As one program director for a local Alzheimer's Association said, "Participating in social activities does not just provide social and cognitive stimulation for both the caregiver and the loved one, but they give each the opportunity to create new social groups for themselves with people who understand their situation."<sup>36</sup>
- Cafés allow care partners to develop social networks and reduce social isolation
- Care partners view memory cafés as a kind of respite and an opportunity to enjoy themselves socially (together with the person who has dementia)
- They provide a space where ADRD is not "in the room" and where people at any stage of disease progression are welcome
- Cafés act as a cost-effective entry point for needed resources and way to support both the person with ADRD and the care partner

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<sup>32</sup> Janis Humphrey, Maureen Montemuro, Esther Coker, Laurie Kilgour-Walsh, Katherine Moros, Carmen Murray, and Shannon Stanners. "Artful Moments: A Framework for Successful Engagement in an Arts-Based Programme for Persons in the Middle to Late Stages of Dementia," *Dementia* 18, no. 6 (August 2019): 2340–60, <https://doi.org/10.1177/1471301217744025>.

<sup>33</sup> Orii McDermott, et al. "The development of Music in Dementia Assessment Scales (MiDAS)," *Nordic journal of music therapy* vol. 24,3 (2015): 232-251, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4487595/>.

<sup>34</sup> Gill Windle, Karlijn J. Joling, Teri Howson-Griffiths, et al., "The Impact of a Visual Arts Program on Quality of Life, Communication, and Well-Being of People Living with Dementia: a Mixed-Methods Longitudinal Investigation," *International Psychogeriatrics* 30, no. 3 (2018): 409–23, <https://doi.org.ezp-prod1.hul.harvard.edu/10.1017/S1041610217002162>.

<sup>35</sup> Gross, Susan M et al, "Creativity and dementia: does artistic activity affect well-being beyond the art class?" *Dementia (London, England)* vol. 14,1 (2015): 27-46, <https://pubmed.ncbi.nlm.nih.gov/24339088/>.

<sup>36</sup> Heidi de Marco, "Finding Connections And Comfort At The Local Café," California Healthline, February 7, 2020, <https://californiahealthline.org/news/memory-café-alzheimers-dementia-patients-socialize-find-connections-and-comfort-at-the-local-café/>.

- Cafés foster participation in social activities and creative and cognitive stimulation that promote improved memory function in persons with ADRD. Many cafés involve music, creative and performing arts because these draw upon aspects of cognitive functioning that are affected last and least by dementia.
  - Café activities stimulate memory in persons with dementia. People with ADRD tend to remember distant, long-ago memories more readily than recent memories. According to one memory café operator: “Ask people to talk about their parents and grandparents, rather than their children or grandchildren. The further people go with dementia, the further back they go with their memories... They are more likely to keep those memories.”
- Cafés offer access to education, information, support, and services for persons with ADRD and their care partners as the diseases progresses. Café’s also provide a link to other community programs such as those offered by the Alzheimer’s Association, Area Agencies on Aging, Aging and Disability Resource Centers, etc.
- Memory café staff can model effective ways to communicate with those who live with ADRD, offering a natural, low-key educational opportunity to care partners.

*“Memory cafés offer a cup of coffee and a connection. Whether they are held at a coffee shop, a museum, a senior or social service center, or other location, each memory café is designed so that people with dementia will feel safe, supported and successful. For care partners (caregivers), they are a much-needed break in the 36-hour day.”*

(source: [MA Memory Café Toolkit](#))

Quotes from memory café operators, caregivers, and those with ADRD provide powerful anecdotal evidence that helps explain the appeal and international growth of memory cafes for persons with dementia and their caregivers:

- *“Memory café activities show that the arts connect us – without need for language or writing.”*
- *“Good feelings about memory café participation are lasting emotions... They remain even if no memory of attending exists.”*
- *“Often, caregivers feel like they can’t go out because they don’t know where their loved ones will be supported. Here, it’s OK if a loved one repeats himself, or the words don’t come out quickly. It’s a safe environment.”*
- *“Caregiving can be a lonely job. Coming to the memory café is a way to let your hair down and empathize with people on the same journey.”*
- *“Dementia can be a cruel ride sometimes. This is the first thing to grab my interest since all this started.”*

Beyond benefiting persons living with ADRD and their care partners, cafés also offer an excellent volunteer opportunity for community members. Volunteers help keep the cost of running a café manageable, and will in turn have the opportunity to interact with people living with ADRD in a positive, educational, strength-based environment that allows them to see the individual rather than the disease. As one advocate has said, “When you’ve met one person with dementia, you’ve met one person with dementia.”<sup>37</sup>

Cafés can also be part of a larger strategy to help communities become more “Dementia (or ADRD) Friendly.” The goal of an ADRD friendly community movement is for individuals with ADRD to live well in communities that offer understanding and various forms of support for them and their care partners. Cafés can bring in participation from many sectors of a community: businesses can contribute food or sponsor a café, local artists or musicians can facilitate activities and, as noted above, students and other people can volunteer. Memory cafés can also act as a source of information about local support services and programs for people with ADRD and their caregivers. By including more community stakeholders and normalizing aging and ADRD, people living with ADRD can continue to find meaning and purpose in their lives despite experiencing memory loss and other cognitive challenges.

See “Section VII. Drivers of Regional Growth and Sustainability” for more information about the “Dementia Friendly” community movement as a viable mechanism for funding, public and policy support for memory cafés, and the roles memory cafés can play in helping communities become more ADRD and caregiver friendly.

## IV. Guidelines for Memory Café Operations: Tips, Strategies and Toolkits

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As mentioned above, there is no single model for a memory café that is preferable over another. Beyond its core mission of offering a safe and inclusive space for people with ADRD and their care partners to socialize, a memory café’s specific activities, structure, and services will vary from café to café. What follows are general tips and strategies for creating and operating a memory café. These guidelines are an amalgam of best practices and expert opinions derived from published memory café toolkits (cited in the Appendix, Table 5), and experiences, including from Susan McFadden, PhD, Professor Emerita, University of Wisconsin Oshkosh. For a summary of available toolkits and other resources for creating memory cafés that we have encountered in our review of the memory café landscape, please refer to the Appendix (Table 5).

### Getting Started: Launching a Memory Café

#### *Forming a Steering Committee*

A recommended first step in creating a memory café is to form a steering committee made up of advocates in the community and represent a diversity of backgrounds and perspectives, including care partners of people with ADRD and others with relevant lived experiences. The members of the committee might include:

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<sup>37</sup> “Understanding Dementia,” Social Care Institute for Excellence, accessed September 21, 2020, <https://www.scie.org.uk/dementia/after-diagnosis/communication/understanding-dementia.asp>.

- People with ADRD and their caregivers
- Professionals working for organizations like the Alzheimer’s Association
- Representatives from local government agencies that work with older populations (e.g., Area Agency on Aging, Councils on Aging, etc.)
- Clergy or others who want to extend a congregation’s services to people with ADRD and their caregivers
- Staff from healthcare organizations who view memory cafés as serving their goals of promoting community health and providing support for persons with ADRD
- Members of local service clubs (such as the YMCA, Elks Club, etc.) who would like to get involved in volunteerism. For example, the Rotary Clubs in the UK were instrumental in starting memory cafés in many communities there.
- Community foundations and other local philanthropic organizations such as the United Way
- Faculty members, staff and students from local colleges and universities who are involved in research, training programs, or policies that affect older adults

The steering committee can support memory café planning and fundraising. Experts recommend that the steering group not be too large and should maintain a focus on inclusive hospitality. Also, that formation of a memory café not be driven by organizations trying to attract their own clients and customers. The steering committee often identifies and appoints a memory café program coordinator who will be responsible for memory café operations.

### *Hiring a Program Coordinator*

A program coordinator can be a staff member at a local organization serving older adults or a staff member at the venue where the café is held, for example a senior center or a library. Ideally, this individual would have prior experience working with people with ADRD. The program coordinator is typically responsible for the following tasks:

- Recruiting, training, and supervising volunteers
- Publicizing the memory café via social media, newspapers, local news and radio stations, as well as partnerships with local organizations for volunteer recruitment and referrals
- Managing the budget
- Planning events for café participants
- Evaluating memory café operations

Given the scope of these responsibilities, the program coordinator is typically (ideally) a paid position (or part of a paid employees’ duties and responsibilities).

Memory cafés often require facilitation support for interactive programming. Sometimes, the program coordinator serves as the facilitator for café programming. However, the coordinator might choose to appoint another individual to serve as the café facilitator. Facilitators can be volunteers, stipended support staff, or in many cases employed by a local organization serving older adults or by the organization that is hosting the memory café. Facilitators can also be artists, musicians, poets, or local celebrities who engage memory café participants and caregivers with entertaining and interactive sessions. For example, Wisconsin’s poet laureate, Karla Huston, has made the memory café movement in her state a focus of her work. Huston shares poetry that will be recognizable to many café guests from their childhood, inviting them to respond both verbally and physically

(participants will act out movements from the poem). She has also facilitated a group creating a poem together with each person at the café contributing a line.<sup>38</sup>

Facilitators should meet with the program coordinator periodically to share information about successes and challenges and to plan memory café events.

### *Identifying Funding Sources and Partnerships*

Memory cafés in the U.S. have been successful in obtaining financial support from a range of different sources. A memory café's steering committee or program coordinator can research any or all of the following options for grants and unrestricted donations:

- Private foundations
- Community foundations
- Alzheimer's Association
- United Way
- Service clubs (such as Rotary Clubs or Elks Clubs)
- Corporate sponsors/local businesses
- Area Agencies on Aging
- Aging and Disability Resources Centers
- State Councils on Aging
- Federal Administration for Community Living (ACL) funding
- Dementia friendly community initiatives (state and municipal)
- Local libraries/library systems
- Faith-based organizations
- Senior centers, YMCAs, and other community organizations

In addition to financial contributions, additional support for memory cafés often comes from organizations that work with aging populations or local business in the form of in-kind donations, for example art supplies, food and beverages, or equipment. Local partners such as Area Agencies on Aging and Alzheimer's Associations frequently donate a range of memory café supports and services.

One recommendation from memory café experts is to begin operations planning and funding exploration through a planning grant. This would allow for an intentional and inclusive process of exploring café models, forming partnerships with local organizations and leaders, seeking out financial and in-kind contributions, and designing marketing, outreach, and recruitment activities.

### *Café Location*

The specific venue of a memory cafe will vary. Cafés have taken place at:

- Coffee houses
- Restaurants
- Community centers
- Senior centers
- Assisted living centers and continuing care communities
- Nature centers
- Galleries/museums

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<sup>38</sup> Jim Higgins, "Wisconsin Poet Laureate Karla Huston Brings Playful Spirit to Memory Café Events," Milwaukee Journal Sentinel (Milwaukee Journal Sentinel, July 11, 2017), <https://www.jsonline.com/story/entertainment/books/2017/07/10/wisconsin-poet-laureate-karla-huston-brings-playful-spirit-memory-cafe-events/461340001/>.

- Libraries
- Churches
- Farms

The principal considerations for selecting a memory café location are that the space:

- Is easy to maneuver with clear signage (where possible, including pictures instead of words)
- Accessible by wheelchair and most other forms of transportation
- Has available parking
- Is conducive for the kinds of events and activities that the café plans to host
- Feels safe, clean, and comfortable
- Has a family-sized, wheel-chair accessible bathroom
- Is relatively quiet with moderate background noise

Churches and other houses of worship can be good locations for memory cafés. Many churches (including in western New York, Michigan, and elsewhere in the U.S.) already play a role in helping to support older adult parishioners and their caregivers, offering drop-off respite programs (such as the [Memory Care Respite Program](#) in western New York), adult day support, and other forms of social congregation. Faith-based organizations can be an effective partner by providing meeting space, in-kind resources, and recruitment support to memory cafés. A helpful resource for faith-based organizations thinking about memory cafés and other support for parishioners with ADRD is a web site titled, [Spirituality and Dementia](#) (developed by affiliates of the [Virginia Theological Seminary](#) with funding from the [Episcopal Evangelism Society](#)).

### *Café Costs*

One of the benefits of memory cafés is that they serve both people living with ADRD and their caregivers at a modest cost. For those starting a café with grant funding, experts recommend keeping costs sustainable from the start so that the program can be sustained if or when grant funding runs out. Practitioners report most cafés cost between \$8,000 and \$15,000 annually, with an additional \$2,500 to \$4,000 in start-up expenses including office supplies. For most cafés, the coordinator's time is the largest expense. Other costs to consider include:

- **Travel costs:** A café may provide or subsidize transportation for some participants to attend. The memory café might also cover transportation for café outings or field trips.
- **Refreshments:** Memory cafés often provide coffee and refreshments for their participants. The least expensive cafés are held at restaurants or coffee shops where guests can purchase their own food or beverages.
- **Programming:** The cost of decorations or supplies varies according to the planned activity. The program coordinator and facilitator should prospectively plan café programming in order to budget the amount that will be spent on decorations and supplies, and to plan/delegate the work. If the café plans on bringing in speakers or artists who require a stipend, stipends would be additional cost.
- **Marketing:** A portion of a memory café budget should be allocated to printing brochures, flyers or posters about the café for distribution around the community. Building and maintaining a website for the café is another potential budget item (a Facebook page can be a lower-cost alternative).

For program coordinators new to the memory café space, sample budgets can be obtained from other café coordinators. For example, a sample budget is provided in this [toolkit](#) from the Massachusetts Department of Developmental services and the Jewish Family & Children’s Service of Greater Boston.<sup>39</sup>

### *Outreach and Marketing*

Because of widespread stigma associated with ADRD—even among those with ADRD themselves and their caregivers—effective marketing is critical for attracting a memory café’s intended audience. Experts recommend that memory café leaders work with clinicians and others who conduct memory assessments and diagnose forms of ADRD so that they can help inform memory café design and recommend café attendance to patients. Flyers and posters can be distributed to the local Area Agency on Aging and other community agencies serving older adults, health care providers, clergy, librarians, and any others who may work with persons with ADRD and their caregivers. In addition to in-person outreach and word-of-mouth efforts, the program coordinator can also disseminate information about the memory café through local media outlets including newspapers, blogs, and radio and television features.

In advance of launching a memory café, program coordinators might also communicate with other local organizations—for example, local foundations, health care organizations, faith-based groups, service clubs, the Area Agency on Aging, Aging and Disability Resource Center, senior centers, etc.—about the broader goal of becoming (advancing or reinforcing) a Dementia Friendly community, and the role and impact of memory cafés in fostering inclusivity and social connectedness. For example, the Fox Valley Memory Café in Wisconsin ran a community breakfast series of information sessions for several months before cafe operations began to discuss this broader goal and the roles memory cafés could play to advance it.

Marketing continues throughout the life of a memory café. Some cafés mail monthly postcard reminders, email newsletters, or send messages via social media. The steering committee, program coordinator, facilitator, and volunteers can all share information via social media to expand awareness about memory cafes. Café operators can set up a webpage or, more simply, a Facebook page for news and updates about the café. (It is important to respect the privacy of memory café participants—any identifying information, pictures, or videos should be posted only with approval of café participants.)

### *Volunteers and Training*

Regular, committed volunteers are important for memory café operations. They help to greet and check participants into the café, distribute nametags, offer refreshments, facilitate conversations, help design and run programs, and remain alert to anyone experiencing any kind of challenge. Volunteers can be recruited through social media and marketing materials at community centers, senior centers, faith-based organizations, service clubs, educational institutions, and other community agencies. For example, cafés might consider forming partnerships with local colleges and high schools that have a community service requirement for their students. For example, students from Brandeis University volunteer at memory cafes sponsored by Jewish Family & Children’s Service of Greater Boston. Care partners whose loved ones have died or have had to move to long-term care can also be good volunteers.

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<sup>39</sup> For a full list of memory café toolkits, visit the Appendix section at the end of this report.

Training: Memory café volunteers must be trained about ADRD broadly, including how it symptomizes, how to best communicate with persons who have ADRD, and how to be sensitive to any signs of physical or emotional distress. Volunteers should also demonstrate an ability to listen attentively while respecting confidentiality. *Volunteers might also need to be trained on basic first aid and complete a background check in most states.* Resources for training can be found at the [Alzheimer's Association](#), which offers many free online videos and informational handouts, and the Dementia Friends program. Dementia Friends is an [hour-long training](#) that covers basic information about ADRD, including how to be a source of support for someone living with ADRD. [Purple Angel Dementia Training](#) is another good resource for memory café community partners and volunteers.

### Other Factors

The success of a memory café is dependent on a variety of factors. Café operators note that fluctuations in attendance, levels of comfort among participants, and the quality of the facilitator and volunteers can all be contributing factors in successful café operations. Practitioners also highlight the importance of interactive engagement for generating enthusiasm and feelings of connectedness. Experts recommend café participants be actively and physically engaged as much as they're able: creating art, crafting, singing, dancing, playing an instrument, and moving along to an activity. These activities offer a way for individuals with ADRD and their caregivers to develop a sense of comfort with each other and can form a basis for conversation and connection. Practitioners also report that too much noise or stimulation should be avoided as it might be disorienting or distressing for some individuals with ADRD. Café facilitators and volunteers will need to be attentive to the needs and changes in mood of the participants and be able to adjust programming accordingly.

### Assessment

Regular assessment of participants' experiences regarding café operations and activities is a recommended way to evaluate a memory café's impact. A simple, anonymous survey—administered following a memory café event—is a valuable way to collect data and inform future planning and budgeting. Example questions include the following (adapted from Wisconsin Memory Café Programs: A Best Practice Guide):

- Are you an individual with ADRD or a care partner?
- If this was your first time attending this memory café, how did you hear about us?
- How often in the past year did you attend this memory café?
- Have you received information about ADRD at the memory café?
- If you received information, how helpful was it?
- Why did you start attending this memory café?
- What influences your decision about attending a memory café?
- What do you most value about the memory café?
- Describe your relationships with other memory café participants.
- How socially connected do you feel with the other memory café participants? (a scale from 1-5 can be used, with “not at all connected” to “very connected” as anchors)
- How could your experiences of memory cafés be improved?
- How does your participation in memory cafés affect your relationship with one another?



- How beneficial is this memory café as a form of respite for you? (a scale from 1-5 can be used, with “not at all beneficial” to “very beneficial” as anchors)
- How would you rate the quality of the staff and volunteers at this memory café? (a scale from 1-5 can be used, with “poor” to “excellent” as anchors)

Practitioners recommend that café experience surveys not be too long: participants will be less likely to respond if there are too many questions, and a taxing questionnaire runs counter to the relaxed café atmosphere goal. Lastly, repeating the same survey questions following café events allows for comparison and the ability to assess changes over time.

### *Additional Suggestions*

Memory cafés are typically slow to get off the ground and build momentum: practitioners report it usually takes about 3-6 months to build and grow attendance. Experts note that it will take time and patience for café coordinators to raise awareness, increase participation and buy in from stakeholders. Also, volunteers may drop out and attendance at memory cafés can be unpredictable. Café coordinators must be adept at assessing and making modifications to the café’s activities and services.

The COVID-19 pandemic has required many memory cafés to move to virtual sessions and activities, particularly since many individuals with ADRD are especially at risk for infection. Operators report that virtual attendance by memory café participants is lower in the current environment compared to in-person attendance prior to COVID-19. Field reports suggest that many memory café coordinators are diverting resources towards training and technical assistance to support online memory café operations and encourage virtual attendance.

## **V. Memory Cafés in the United States Today**

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### **The Memory Café Directory and Other National Resources**

#### *National Resources*

Nearly 900 memory cafés operating in the U.S. today are now listed in the Memory Café Directory, [an online repository](#) that catalogues self-identifying memory cafés in all 50 states and around the world (the actual number of memory cafes in operation is likely greater). Also available on the Directory is a [calendar](#) of virtual memory café events that participants can join remotely (a feature that is especially important due to COVID-19). Besides providing listings organized by state, region, and city, the Directory offers resources for caregivers, those who are interested in starting a memory café, and those who are looking to promote an existing café. As of September 2020, the states with the most memory cafés are (number of memory cafés is included in parentheses):

- |                        |                        |
|------------------------|------------------------|
| 1) Wisconsin (139)     | 6) Minnesota (36)      |
| 2) Massachusetts (130) | 7) Pennsylvania (28)   |
| 3) Illinois (40)       | 8) North Carolina (22) |
| 4) Washington (37)     | 9) Virginia (22)       |
| 5) Texas (37)          | 10) Florida (21)       |

Other resources and information about memory cafés can be found at: [Grantmakers in Aging](#), [American Society on Aging](#), [Area Agencies on Aging](#), [Alzheimer's Association](#), [Alzheimer's Foundation](#), [National Alzheimer's and Dementia Resource Center](#), and [the Administration for Community Living](#). While none of these organizations or associations focus exclusively (or primarily) on memory cafés, a number of them offer their own directories, webinars, informational videos, examples of funded/existing cafés, and reading materials for café organizers and for individuals interested in attending a café or learning about memory cafés.

## Best Practices: Wisconsin and Massachusetts

### *Memory Café Best Practices: Wisconsin*

In Wisconsin, community stakeholders, funders, academic institutions, libraries, and public health agencies have worked together to foster an ADRD friendly ethos throughout the state, a value further reflected by the number of memory cafés in the region. There are currently 139 Wisconsin memory cafés registered in the Memory Café Directory. Two early, prominent examples of memory café networks in Wisconsin include the [Fox Valley Memory Project](#) and the [Library Memory Project](#):

#### ➤ [Fox Valley Memory Project](#)

Susan H. McFadden, PhD, Professor Emerita of Psychology at University of Wisconsin, Oshkosh, co-founded Fox Valley Memory Project (FVMP) in 2012. From its inception, FVMP was intentional about collecting input from elderly adults and caregivers about memory café design, planning, and operations. FVMP is financed through a combination of funding from Bader Philanthropies, a local community foundation, the United Way, Rotary Club, other donors and fundraisers, and in-kind donations from memory café host organizations and local restaurants. (Unlike some states, funding from government agencies in Wisconsin has thus far been limited.) Prior to the pandemic, FVMP operated nine monthly memory cafés in eight different locations. Like many memory cafés during the pandemic quarantine, it has shifted its programming to Zoom and now offers two different Zoomed cafes each week.

Besides the typical activities and opportunities for socialization that memory cafés offer, FVMP services include a memory loss resource center, a memory assessment center, community education, and outreach to long-term care providers. In part to help coordinate these initiatives, FVMP employs a full-time director and a part-time program coordinator. Survey data from café attendees indicate that FVMP's cafés have helped participants combat social isolation, recall personal memories, and take part in opportunities for community engagement. Participants also report that the memory café provides family and care partners with a shared experience and fosters meaningful connections among loved ones and friends.

#### ➤ [The Library Memory Project](#)

Launched in 2015 with the Bridges Library System, the Library Memory Project (LMP) consists of 13 libraries across three counties in southeast Wisconsin that partner together in offering 36 discrete memory café events and educational opportunities each year. LMP partners with the Alzheimer's Association of Southeast Wisconsin for operations support. Like FVMP, major funding for this program is also provided by Bader Philanthropies.

Each month, LMP hosts 90-minute monthly memory café meetings attended by 500-600 participants each year. The time is split between group activities and general socialization. Separate educational programs for caregivers are also provided.

Wisconsin's culture of centering and normalizing those with ADRD and their caregivers is also supported by the [Wisconsin Dementia Resource Network](#) (WDRN). Created in 2017 in partnership with the Wisconsin Alzheimer's Institute at the University of Wisconsin School of Medicine and Public Health, WDRN is a collaboration of statewide partners that aims to share innovative best practice and resources related to ADRD. One of their products is a memory café toolkit, [Wisconsin Memory Cafés: A Best Practice Guide](#) (see the Appendix for this and other published toolkits).

### *Memory Café Best Practices: Massachusetts*

Among Massachusetts' 130 memory cafés, the Create a Better Day Café (founded in 2011 by Tammy Pozerycki) was the first. This memory café has a special focus on the creative arts since they “[require] capacities that tend to be spared by dementia-causing diseases.” Group art experiences are used to spark a greater sense of connectedness among participants and bring those with ADRD and their care partners closer together.

In 2014, Jewish Family and Children's Services (JFCS) began Massachusetts' second memory café. JFCS also hosts a monthly “intergenerational” event through its corps of volunteers from Brandeis University. By seeking out student volunteers, the Café addresses the broader goal of reducing stigma around ADRD at a community-wide level.

In 2014, JFCS, with financial support from the Massachusetts Councils on Aging, launched the [Percolator Memory Café Network](#) (PMCN) to support those starting or sustaining memory cafés in Massachusetts and beyond. (The Percolator Memory Café Network's toolkit for starting an MC is also listed in the Appendix.) The Network has supported the launch of over 100 new cafés in Massachusetts including two Spanish-speaking cafés, one Chinese-speaking café, and one Portuguese-speaking café. Thirteen PMCN-member cafés in Massachusetts are specifically designed for people who have both ADRD and a developmental disability. Via PMCN, cafés are able to search for and utilize the talents of 62 teaching artists who lead activities like dance, singing, drumming, theater games, poetry writing, and art making. Today the Percolator Network has grown to represent hundreds of organizations in Massachusetts, nationally, and a few international attendees who participate in memory café events. Over 2,500 caregivers and persons with ADRD participate in at least one café activity annually through JFCS programs.

In 2015 and 2016, three statewide organizations offered seed grants to fund new cafés: the Massachusetts Lifespan Respite Coalition, the Massachusetts Association of Councils on Aging, and the Massachusetts Department of Developmental Services (the latter was the first in the nation to support integrated memory cafés that serve individuals with both ADRD and a developmental disability). The memory café movement in Massachusetts is also supported and promoted through partnerships with Dementia Friends Massachusetts, state agencies like the Massachusetts Executive Office of Elder Affairs and the Massachusetts Councils on Aging, Alzheimer's Association, Tufts Health Plan Foundation, and other philanthropic organizations.

In addition, in 2017, the Massachusetts Association of Councils on Aging and a group of senior center operators received a three-year grant from the federal Administration for Community Living’s Specialized Supportive Services program. Through this ACL grant, memory café operations are expanding specifically in underserved and minority communities in Massachusetts and to support persons with intellectual and developmental disabilities and ADRD.

## Memory Cafés in New York and Michigan

### *Memory Cafés in New York State*

According to the Memory Café Directory, there are currently 14 memory cafés operating in New York State. Four are located in the New York City-Brooklyn area: the New York Memory Center (described below), the Dale Jones Burch Neighborhood Center, the NYU Central Park Social Gathering Space (Family Support Program Memory Café/NYU Department of Psychiatry), and Riverstone Senior Life Services.

The New York Memory Center’s Memory Arts Café in Brooklyn offers a series of free cultural events for people living with ADRD, their caregivers, family members, and friends. Co-produced by the New York Memory Center and the Alzheimer’s Poetry Project, the café takes advantage of the city’s vibrant arts scene by featuring local professional artists including musicians, magicians, poets, and dancers. Interestingly, this memory café is also open to the general public so that community members who have no relationship to individuals with ADRD or their caregivers are able to appreciate the programs and interact with café participants. The café is partially funded by Axe-Houghton Foundation, Brooklyn Arts Council, New York State Department of Health, and the Poetry Foundation, with further support and partial funding from 305 West End Ave. Assisted Living.

In other parts of the state, memory cafés operate at the following locations:

Name	Location
Memory Café Concert Series at West Falls Center for the Arts	West Falls
Comfort Today Adult Day Services	Jamestown
Comfort Today Adult Day Services	West Ellicott
Happy Hearts Memory Café at Stone Presbyterian Church	Watertown
Syracuse Memory Café at Pebble Hill Presbyterian Church	Dewitt
Clubhouse Bro’s Family Restaurant	Wheatfield
Alzheimer’s Association/St. Andrew’s Episcopal Church	Yaphank
Memory Café at NNY (held at United Community Center)	Philadelphia
Butera’s Restaurant of Sayville	Sayville
How Sweet It Is Memory Café at Shaarei Tikvah Synagogue	Scarsdale

New York’s memory cafés have been promoted by Alzheimer’s Association Chapters (including its Western New York chapter) and (potentially) through the New York State Department of Health’s Alzheimer’s Disease Program, which in 2016 made a \$25M grant to fund community-based supports for persons with ADRD over the next five years. In western New York and Monroe County,

recipients of Alzheimer’s Disease Program grant funding include: SUNY Buffalo’s Center for Excellence in Alzheimer’s Disease, Pride Center, Catholic Charities of Buffalo, Alzheimer’s Association - WNY Chapter, Chautauqua Opportunities, Alzheimer’s Association - Rochester and Finger Lakes Region, Lifespan of Greater Rochester, Inc., and University of Rochester Medical Center.

Also, in western New York, several faith-based organizations run Memory Care Respite Programs. Unlike the memory café model, these are ‘drop-off’ respite programs, where caregivers can safely drop their caree off for several hours (social day support) so that the caregiver can run errands, take care of personal needs or emotional wellbeing, etc.

### *Memory Cafés in Michigan*

The Memory Café Directory lists nine memory cafés in Michigan:

Name	Location
Lewanee Memory Café at Adrian Dominican Life Center	Adrian
Kate’s Memory Café (Helping Hands Respite Care) at Valley Court Community Center	East Lansing
Grace Lutheran Church	Gwinn
Jackson District Library (Meijer Branch)	Jackson
Civic Park Senior Center (Alzheimer’s Association Greater MI Chapter)	Livonia
Marquette Adult Day Services at Messiah Lutheran Church	Marquette
Paw Paw District Library	Paw Paw
Memory Café at NNY (held at United Community Center)	Philadelphia
Joe’s Memory Arts Café at St. Joseph Mercy Hospital	Ypsilanti
We Care Connect Memory Café at Ypsilanti Senior Center	Ypsilanti

Michigan’s memory cafés are promoted by Alzheimer’s Association chapters across the state. For example, Alzheimer’s Association of West Michigan sponsors three cafés twice monthly in Kent County: Easttown Memory Café at Wolfgang’s Restaurant, Grandville Memory Café at Russ’ Restaurant, and Grand Haven Memory Café at Two Yolks’ Café (note: these three cafes do not appear in the Memory Café Directory and therefore are not listed in the table above).

“[We Care Connect Memory Café](#)” at Ypsilanti Senior Center emphasizes activities for its participants that address holistic wellness including exercises for improving the mind-body connection and relaxation exercises. This café also makes efforts to be responsive to the specific needs of its participants. For example, after someone requested more information about the challenges inherent in traveling with someone who has ADRD, the café hosted a livestream presentation from a travel agency that specializes in supportive cruises and vacation experiences for people with ADRD and their care partners.

## Other Examples of the Memory Café Model

Indiana's [Connor Prairie Memory Café](#) is hosted at a 1000-acre farm in partnership with Dementia Friends Indiana and the Central Indiana Council on Aging. Monthly themes vary: for example, one recent activity involved games and toys that people with ADRD might have played with as children or as parents. Other popular themes at Connor Prairie have included a swing band concert and time with baby goats and lambs. The farm setting allows participants to be in nature and, perhaps, revisit a place that is part of their past identities.

Another variant of the memory café model is [Alz Meet Ups](#), a program for individuals who are in the early stages of ADRD (Alz Meet Ups is frequently sponsored by Alzheimer's Association local chapters). The goals are the same as in any memory café: participants are able to be active, socialize, and get connected with one another through a variety of social events and community-based activities. At the same time, participants and their families are able to meet local people and families who, like them, are new to the ADRD space and who are perhaps just learning to cope with the ADRD diagnosis. Alz Meet Ups are hosted regularly throughout Massachusetts, New Hampshire, and other states. The San Francisco-based Memory Care Café is another memory café that primarily targets individuals who are in the early stages of ADRD.

Finally, Virtual Memory Cafés is a memory café model sponsored by [Dementia Mentors](#). Rather than meeting at a physical location, participants meet online via a computer with a webcam and a microphone. Given the fewer “barriers to entry,” groups are able to meet weekly rather than monthly, and operational costs are lower compared to those of a typical memory café. Currently, Dementia Mentors hosts 26 virtual cafés with participants joining from all over the world. As in an in-person memory café, participants at a Virtual Memory Cafés event are brought together to socialize, share support, and feel a greater sense of connection. One unique feature of Virtual Memory Cafés is that they are designed specifically for individuals with ADRD and not their care partners.

Virtual memory cafés have become more popular during the COVID-19 pandemic as physical gatherings may carry too high of a risk for memory café participants. The necessities of the current environment have reinforced the need to pivot operationally and utilize new technologies to achieve the goals of memory cafés. And, as we will discuss in the next section, virtual memory cafés offer a model and learnings that might be applied to other adult populations beyond those with ADRD and their care partners.

## VI. Memory Café Applications for Other Older Adult Populations

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As explored in our discussion of social isolation and loneliness (see “Section III. Benefits of Memory Cafés”), memory cafés may also serve a purpose for populations outside of those with an ADRD diagnosis and their caregivers. The services offered by cafés could provide benefits to a wider audience of other older adults, producing an amelioration of the negative effects caused by social isolation (including the onset of ADRD), along with a larger, broad-based destigmatizing not only of ADRD but also the experience of aging as a whole.

## Socially Isolated Older Adults

The population of older adults in the United States is rapidly growing, with the number of Americans ages 65 and older expected to double over the next 40 years.<sup>40</sup> What's more, the proportion of older adults who live alone, and who are more likely to experience social isolation, has become increasingly pronounced. The 2018 United States Census reported that, whether by choice or by circumstance, one out of five adults age 65 to 74 years old live alone, a figure that doubles to roughly 4 out of 10 among those 85 and older.<sup>41</sup> This has steadily trended upwards over time: between 1900 and 2014, the share of adults ages 65 and older living alone increased from 6 percent to 26 percent.<sup>42</sup> Older adults might live alone for any number of reasons: separation from or the death of a partner; the increased likelihood of having fewer children or children moving away; loss of physical mobility and other comorbidities; and the high cost of senior retirement communities.<sup>43</sup>

While living alone in and of itself is not directly associated with adverse health effects, it may be used as a measure for and predictor of social isolation. As mentioned earlier, social isolation can be defined as the absence of social interactions, contacts, and relationships on a structural level, a state that is compounded when the individual lives by him or herself.<sup>44</sup> According to a study from the Pew Research Center, compared with older adults who live with someone else, older adults who live alone have less frequent contact with children, grandchildren, and other family members. They are also less likely to spend their time pursuing hobbies or volunteer work.<sup>45</sup> Moreover, older people are at higher risk for social isolation due to their physical frailty, in addition to deaths in their family and friend networks.<sup>46</sup>

The actual health effects of social isolation have been well documented. It represents a major source of mental or psychosocial stress that increases the prevalence of neurological diseases.<sup>47</sup> A study from the National Academies of Sciences, Engineering, and Medicine reported that social isolation was associated with about a 50 percent increased risk of ADRD.<sup>48</sup> In addition, individuals with ADRD are more likely to suffer from social isolation due to their loss of communication and an increased likelihood of social neglect; in other words, not only will social isolation accelerate cognitive decline and the onset ADRD, an ADRD diagnosis will accelerate social isolation.<sup>49</sup>

To this end, socially isolated older adults may be cut off from certain benefits and resources for which they are eligible. For example, they may be less likely to visit their local Social Security office

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<sup>40</sup> "The US Population Is Aging," Urban Institute, April 3, 2015, <https://www.urban.org/policy-centers/cross-center-initiatives/program-retirement-policy/projects/data-warehouse/what-future-holds/us-population-aging>.

<sup>41</sup> Andrew W. Roberts, Stella U. Ogunwole, Laura Blakeslee, and Megan A. Rabe, "The Population 65 Years and Older in the United States: 2016," American Community Survey Reports (United States Census Bureau), October 2018, <https://www.census.gov/content/dam/Census/library/publications/2018/acs/ACS-38.pdf>

<sup>42</sup> Renee Stepler, "Smaller Share of Women Ages 65 and Older Are Living Alone," Pew Research Center's Social & Demographic Trends Project, August 26, 2020, <https://www.pewsocialtrends.org/2016/02/18/smaller-share-of-women-ages-65-and-older-are-living-alone/>.

<sup>43</sup> "Senior Isolation: America's Quietest Health Risk," In Your Golden Years, accessed September 21, 2020, <https://inyourgoldenyears.com/2018/08/senior-isolation/>.

<sup>44</sup> "Social Isolation Among Older Individuals: The Relationship to Mortality and Morbidity," The Second Fifty Years: Promoting Health and Preventing Disability, U.S. National Library of Medicine, January 1, 1992, [www.ncbi.nlm.nih.gov/books/NBK235604/](http://www.ncbi.nlm.nih.gov/books/NBK235604/).

<sup>45</sup> Renee Stepler, "Smaller Share of Women Ages 65 and Older Are Living Alone," Pew Research Center's Social & Demographic Trends Project, August 26, 2020, <https://www.pewsocialtrends.org/2016/02/18/smaller-share-of-women-ages-65-and-older-are-living-alone/>.

<sup>46</sup> Eric Klinenberg, "Social Isolation, Loneliness, and Living Alone: Identifying the Risks for Public Health," *American Journal of Public Health*, 106(5) (2018): 786–787, <https://doi.org/10.2105/AJPH.2016.303166>.

<sup>47</sup> B. Friedler, J. Crapser, and L. McCullough, "One is the deadliest number: the detrimental effects of social isolation on cerebrovascular diseases and cognition," *Acta Neuropathol* 129 (2015): 493–509, <https://doi.org/10.1007/s00401-014-1377-9>.

<sup>48</sup> *Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System* (Washington, DC: the National Academies Press, 2020).

<sup>49</sup> Luz María Peña-Longobardo and Juan Oliva-Moreno, "Caregiver Burden in Alzheimer's Disease Patients in Spain," *Journal of Alzheimer's Disease*, 43(4) (2015), 1293-1302, <https://content.iospress.com/articles/journal-of-alzheimers-disease/jad141374>.

to ensure they are receiving their proper benefits or enroll in Medicare. Isolated adults may neglect participating in programs like Meals on Wheels that benefit their health and wellbeing, and they are less likely to seek out proper medical care. Social isolation and the pattern of continued isolation it produces constitute a grave health risk to older adults with or without ADRD, but perhaps most urgently among those living in rural areas.<sup>50</sup>

## Social Isolation in Rural Areas

The weakness or absence of social networks are heavily influenced by environmental factors, namely where the individual lives and his or her physical ability to access social support. Accordingly, older adults living in rural areas have a disproportionate risk of becoming socially isolated. A survey conducted by the U.S. Census Bureau found that 10.6 million or 23 percent of those aged 65 and older are living in areas designated as rural.<sup>51</sup> These individuals face special challenges due to their rural surroundings. Older rural adults were less likely to live in nursing homes and less likely to have educational attainment beyond a high school degree compared to their urban counterparts. Thirty-six percent of older rural adults reported living with a physical disability. These factors have a significant impact on the degree to which older rural adults may become socially isolated, as they become less likely to access hospital and rehabilitation facilities, attend an educational or enrichment programs, and join assisted living and skilled-nursing facilities.<sup>52</sup> According to a study from The Gerontological Society of America, approximately three in five older rural adults have feelings of loneliness at one time or another, with another one in five reporting much loneliness.<sup>53</sup> Another study of rural adults found that the loss of a partner, decreases in vision, problems of transportation, and low participation in organized social activities all increased the frequency of older rural adults feeling lonely.<sup>54</sup>

It is perhaps unsurprising that living in a rural environment might have an effect on rates of ADRD. One meta-analysis documented in the *International Journal of Epidemiology* found a higher risk of ADRD associated with rural living.<sup>55</sup> Further, rurality may contribute to ADRD being underdiagnosed: a study of Medicare beneficiaries in Kentucky and West Virginia concluded that ADRD was underdiagnosed among those living in rural areas compared to their urban counterparts. The researchers hypothesized that not only were older rural adults less likely to be identified as having ADRD, they were also more likely to receive sub-optimal care once they were properly diagnosed.<sup>56</sup>

## Social Isolation and Caregivers

The physiological and psychological effects of having to care for individuals with ADRD have been well documented. Still, particular attention might be paid to care partners who, as a result of the specific kinds of behavioral and cognitive deterioration associated with ADRD, will have a higher

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<sup>50</sup> "Elder Abuse," Caring.com, accessed September 21, 2020, <https://www.caring.com/articles/aging-and-loneliness-epidemic>.

<sup>51</sup> Amy Symens Smith and Edward Trevelyan, "The Older Population in Rural America: 2012–2016," *American Community Survey Reports* (United States Census Bureau), September 2019, <https://www.census.gov/content/dam/Census/library/publications/2019/acs/acs-41.pdf>.

<sup>52</sup> *Ibid.*

<sup>53</sup> Anita Liberalesso Neri, Mônica Sanches Yassuda, *et al.*, "Relationships between Gender, Age, Family Conditions, Physical and Mental Health, and Social Isolation of Elderly Caregivers," *International Psychogeriatrics* 24, no. 3 (2012): 472–83, <https://pubmed.ncbi.nlm.nih.gov/21929829/>.

<sup>54</sup> VR Kivett, "Discriminators of loneliness among the rural elderly: Implications for intervention," *The Gerontologist*, 19(1), (1979): 108–115, <https://doi.org/10.1093/geront/19.1.108>.

<sup>55</sup> Tom C Russ, *et al.*, "Geographical variation in dementia: systematic review with meta-analysis," *International journal of epidemiology* vol. 41,4 (2012): 1012–32, <https://pubmed.ncbi.nlm.nih.gov/22798662/>.

<sup>56</sup> Erin L. Abner, *et al.*, "Rural-Urban Differences in Alzheimer's Disease and Related Disorders Diagnostic Prevalence in Kentucky and West Virginia," *The Journal of rural health : official journal of the American Rural Health Association and the National Rural Health Care Association* vol. 32,3 (2016): 314–20, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5056321/>.



risk of experiencing social isolation. A study published in *The Gerontologist* found that caregivers of people with ADRD were nearly 15 percent more likely than other caregivers to give up on hobbies, vacations, and other pleasurable activities. They were also 14 percent less likely to spend time with other relatives.<sup>57</sup> Caregivers co-residing with their care recipients were 2.5 times more likely to feel socially isolated, and those who felt there was an unmet need for long-term care services were nearly four times more likely to feel isolated.<sup>58</sup> The fact that a number of caregivers are themselves older is also a complicating factor: a study from *International Psychogeriatrics* of elderly caregivers found the perception that one's social support was low significantly increased the risk of the caregiver having chronic health issues almost three-fold.<sup>59</sup> What's more, social isolation—and resulting depressive symptoms and emotional strain—seems to have a cyclical effect. Individuals who live with highly distressed caregivers are more likely to have intensified behavioral problems, including agitation and aggression, which will in turn lead to a greater propensity on the caregiver's part to self-isolate.<sup>60</sup>

## Benefits of Memory Cafés for Socially Isolated Older Adults

While direct research into the potential benefits of memory cafés for socially isolated adults (including those in rural settings) is unavailable, the possible use of memory cafés – or a similar adaptation – as a tool or strategy to address social isolation among older adults is apparent. Numerous studies looking at specific interventions have demonstrated a positive association between activities typically associated with memory cafés and the reduction of social isolation among older adults. For example, researchers looking at older rural communities in Ireland recommend building social networks and active involvement in the community as a means to alleviate social isolation.<sup>61</sup> Another investigation published in the *International Journal of Geriatric Psychiatry* found group-based therapy, specifically reminiscence therapy, to be effective in reducing social isolation and generating feelings of connectedness.<sup>62</sup> Researchers have found group physical activities and games offer a compensatory strategy for social isolation and loneliness.<sup>63</sup> A gardening program had a similar effect on nursing home residents in strengthening social bonds and reducing isolation.<sup>64</sup>

*In considering the core characteristics of memory cafés, we see a strong overlap in the types of activities that would potentially benefit socially isolated adults: conversation, socializing with others, activities that promote physical, mental and creative engagement. Given these similarities and the interconnectedness of social isolation and ADRD, it is reasonable to assume that memory cafés, which see a positive effect on the health outcomes and*

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<sup>57</sup> Marcia G. Ory, PhD, MPH, *et al.*, "Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers," *The Gerontologist*, Volume 39, Issue 2 (April 1999): 177–186, <https://doi.org/10.1093/geront/39.2.177>.

<sup>58</sup> J. Robison, R. Fortinsky, *et al.*, "A Broader View of Family Caregiving: Effects of Caregiving and Caregiver Conditions on Depressive Symptoms, Health, Work, and Social Isolation," *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences* 64B, no. 6 (2009): 788–98, <https://doi.org/10.1093/geronb/gbp015>.

<sup>59</sup> Julie Robison, *et al.*, "A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation," *The journals of gerontology. Series B, Psychological sciences and social sciences* vol. 64,6 (2009): 788–98, <https://pubmed.ncbi.nlm.nih.gov/19518470/>.

<sup>60</sup> R. Schulz and G.M. Williamson, "A 2-year longitudinal study of depression among Alzheimer's caregivers," *Psychology and aging* vol. 6,4 (1991): 569–78, <https://pubmed.ncbi.nlm.nih.gov/1777145/>.

<sup>61</sup> D. Heenan, "How Local Interventions Can Build Capacity to Address Social Isolation in Dispersed Rural Communities: A Case Study from Northern Ireland," *Ageing Int* 36, 475–491 (2011), <https://doi.org/10.1007/s12126-010-9095-7>.

<sup>62</sup> Kai-Jo Chiang, *et al.*, "The effects of reminiscence therapy on psychological well-being, depression, and loneliness among the institutionalized aged," *International journal of geriatric psychiatry* vol. 25,4 (2010): 380–8, <https://pubmed.ncbi.nlm.nih.gov/19697299/>.

<sup>63</sup> Patricia E. Kahlbaugh, Amanda J. Sperandio, Ashley L. Carlson & Jerry Hauselt, "Effects of Playing Wii on Well-Being in the Elderly: Physical Activity, Loneliness, and Mood," *Activities, Adaptation & Aging* 35:4, (2011):331–344, <https://doi.org/10.1080/01924788.2011.625218>.

<sup>64</sup> Mimi Mun Yee Tse, "Therapeutic effects of an indoor gardening programme for older people living in nursing homes," *Journal of clinical nursing* vol. 19,7–8 (2010): 949–58, <https://pubmed.ncbi.nlm.nih.gov/20492039/>.

*wellbeing of those with ADRD and their care partners, would see similar effects on socially isolated adults.*

The performing arts are a central piece of the programming offered by memory cafés, and their effects on combating social isolation is encouraging. Group singing has been shown to decrease feelings of loneliness and improve social and emotional bonding among older adults.<sup>65,66</sup> In fact, the specific influence of music on promoting social bonding has been shown to be stronger compared to crafts or creative writing projects undertaken as a group.<sup>67</sup> One study found that singing and music listening in a group can confer long-term emotional and social benefits for both people with ADRD and their caregivers.<sup>68</sup> And a theater arts initiative that facilitated intergenerational performance and dialogue was found to reinforce notions of community by affirming and acknowledging the lived experiences of older adults as members of the community.<sup>69</sup>

The literature addressing social isolation in older adults, rural social isolation, caregiving and isolation, and the benefits of components or characteristics of memory cafés in reducing social isolation among older adults is summarized in the Appendix, Tables 3 and 4.

Finally, as discussed in a previous section, the COVID-19 pandemic has required a shift of memory café programming and services towards virtual offerings. Growing learnings about how to best utilize technology in order to work with home-bound adults with ADRD and their caregivers may be broadened to include other older adult populations, for example those individuals whose social isolation is due to geography—specifically older rural adults—and those for whom transportation to a café is a limiting constraint. Current, ongoing reallocation of resources to augment technology for memory café providers and their participants might be applied to other adult populations for whom access to memory café sites might be similarly challenging. Further, the pandemic has brought into sharper relief the ways in which organizations that incorporate performing arts into their offerings face new demands to create digital programs that help to mitigate the effects of social isolation.

In order to address social isolation among other older adult groups and effectively appeal to broader populations, some re-design of memory café operations and activities, re-alignment of community partnerships, and re-design of outreach and marketing strategies would likely be necessary. For example, exploration or experimentation with different names could address whether the term ‘memory café’ will appeal to older adults who are not living with ADRD. Or in considering café outreach, more emphasis might be placed on marketing to or partnering with entities that serve rural communities such as local rural health networks, regional grange networks, [USDA Rural Development](#), or the [National Rural Health Association](#). Exploration of memory café appeal and adaptations for use with older adults who may be experiencing social isolation (such as older adults who live alone, rural older adults, and many caregivers) could lead to new variations in memory café

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<sup>65</sup> Susan Maury and Nikki Richard, “A Comparison of the Effects of Short-Term Singing, Exercise, and Discussion Group Activities on the Emotional State and Social Connectedness of Older Australians,” *Music & Science*, vol. 1 (2018), <https://doi.org/10.1177%2F2059204318800607>.

<sup>66</sup> Divya Mathew, *et al.*, “Music Therapy as Group Singing Improves Geriatric Depression Scale Score and Loneliness in Institutionalized Geriatric Adults with Mild Depression: A Randomized Controlled Study,” *International Journal of Educational and Psychological Researches*, vol. 3, no. 1, 2017, pp. 6–10, <http://www.ijepjournal.org/article.asp?issn=2395-2296;year=2017;volume=3;issue=1;spage=6;epage=10;aulast=Mathew>.

<sup>67</sup> Eiluned Pearce, Jacques Launay, and Robin I. M. Dunbar, “The Ice-breaker Effect: Singing Mediates Fast Social Bonding,” *Royal Society Open Science* 2, no. 10 (2015): 150221, <https://doi.org/10.1098/rsos.150221>.

<sup>68</sup> Teppo Särkämö, *et al.*, “Cognitive, emotional, and social benefits of regular musical activities in early dementia: randomized controlled study.” *The Gerontologist* vol. 54,4 (2014): 634-50, <https://pubmed.ncbi.nlm.nih.gov/24009169/>.

<sup>69</sup> Sharon Anderson, *et al.*, “Translating Knowledge: Promoting Health Through Intergenerational Community Arts Programming,” *Health Promotion Practice* 18, no. 1 (2017): 15-25, <https://journals.sagepub.com/doi/abs/10.1177/1524839915625037>.

models, broader applications beyond the ADRD community, and, as a result, increased café proliferation.

## VII. Drivers of Memory Café Regional Growth and Sustainability

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Analysis of the growth of memory cafés in states like Wisconsin and Massachusetts where they have flourished suggests the following factors positively influence the regional growth and sustainability of memory cafés:

- **Available Local Funding** – As previously mentioned, program coordinators, café sponsors, or steering committees can seek out local seed funding for individual café start-up or expansion. In this environmental scan, the following sources of funding were identified:
  - **Foundation Funding** – Local community foundations and other regional funders like Bader Philanthropies often support memory cafés. Foundation grants have variously financed memory café planning, operations, regional expansion, technical assistance support and regional networking opportunities for memory cafés. These same funders (also, health foundations) support age and dementia friendly community movements that effectively support memory cafés and a range of other activities that advance community-based services and wellbeing for persons with ADRD.
  - **State and County Funding** – Government-funded agencies that serve older adults, such as Area Agencies on Aging, Councils on Aging, Aging and Disability Resource Centers, can be a source of café funding and frequently assist with café operations – providing professional services, access to community resources for older adults, and other supports.
  - **Municipal Funding** – Library, school, community center, and other municipal funds can (in some regions) support memory café operations. Municipal organizations also provide café meeting venues, staffing, in-kind donations, community outreach and advertising support for memory cafés.
  - **Alzheimer’s Association** – Local Alzheimer’s Association chapters often provide funding and a range of in-kind supports to memory cafés such as counseling, referrals, and ADRD information for participants and caregivers.
  - **Community Organizations** – The United Way, YMCA, faith-based organizations, and other community-based organizations can be sources of funding, meeting space, refreshments and other in-kind donations, volunteers, outreach, and recruiting support for memory cafés.
  - **Health and Social Service Organizations that Serve Older Adults** – Senior centers, acute and long-term care health providers, and assisted living facilities often host memory cafés, help with recruitment, provide staff support, and offer a range of services to support café operations.
  - **Businesses** – Local businesses, especially restaurants, frequently provide funding, meeting space, refreshments and supplies, volunteers, and marketing support. Practitioners recommend putting in writing the terms of memory café partnership—what is requested and what is offered in return.

- **Participant Fees** – Some memory cafés charge a participant entrance fee to help cover the costs of operations.
- **State and County Agencies** – [Area Agencies on Aging](#), [Councils on Aging](#), [Aging and Disability Resource Centers](#), and other government-funded agencies are typically excellent partners for memory café recruitment and operations. As noted above, state and county agencies frequently provide professional staff and services, access to a wide range of community-based aging services, and information to café operators, participants, and caregivers. They also often serve as a resource where café participants can be referred for additional help or services. These agencies are also proficient at identifying and recruiting persons with ADRD and caregivers who might wish to attend a café.
- **Favorable State and Local Policy** – State and local government policy support and funding for dementia friendly communities are extremely favorable to memory cafés and their growth. Memory cafés create accessible, low-cost, ADRD friendly spaces and gathering opportunities in communities. A favorable policy and community atmosphere can also galvanize community partners to fund and support memory cafés and make participant and volunteer recruitment easier.
- **Local Champions** – In states where memory café growth is robust, there are local champions—visible and vocal advocates for memory café expansion, funding, and support—people who connect the memory café movement with local age and ADRD friendly community movements for added funding, policy, and public support. In Wisconsin, a memory café champion is Susan McFadden, PhD, a co-founder of the [Fox Valley Memory Project](#). In Massachusetts, a key champion is Beth Soltzberg, MSW of [Jewish Family & Children’s Services](#). Soltzberg is the founder of several memory cafés and the [Percolator Memory Café Network](#).
- **Incubator Resources and Technical Assistance for Emerging Cafés** – Memory café growth is significantly advanced by the presence of a collaborative network of memory cafés—a go-to resource that provides guidance on memory café best practice, connection to funding and policy support, and operations expertise—helping memory cafés start and replicate. Collaborative memory café networks typically provide a range of member services, including quarterly presentations and peer exchange opportunities, training and technical assistance, how-to information/resources and standards for café operations, an online member directory, a guest facilitator or artist directory, assistance with grant applications, and support for public outreach and awareness. States leading the U.S. in memory café growth have funded and staffed memory café incubators and technical assistance resources for local cafés. For example, the [Percolator Memory Café Network](#) in Massachusetts, and in Wisconsin, the [Wisconsin Dementia Resource Network/ Wisconsin Alzheimer’s Institute](#) and [Fox Valley Memory Project](#) play this role.
- **Public and Community Support** – Age and dementia friendly communities are supportive atmospheres where memory cafés can thrive. A supportive community results in greater public awareness of memory cafés and their benefits, which in turn results in more donations, volunteers, and other in-kind support from area businesses, restaurants, or community groups who might seek to affiliate with or support memory cafés.

- **Local Media** – Local media can be a powerful tool for outreach and raising awareness about memory cafés. Forming contacts with local television, print, and radio media can elevate the role and visibility of memory cafés, share participant experience, and support recruitment and marketing efforts.

It is often a confluence of factors that creates the most favorable conditions for regional growth and sustainability of memory cafés. For example:

#### **In Massachusetts:**

- Funding from the Massachusetts Councils on Aging (2014) supported the Jewish Family & Children’s Services to develop the Percolator Memory Café Network and (in 2016) a Memory Café Toolkit.
- Seed grants to new cafés were offered by three statewide organizations in 2015-16: the Massachusetts Lifespan Respite Coalition, the Massachusetts Association of Councils on Aging, and the Massachusetts Department of Developmental Services.
- In 2017, an ACL grant to the Massachusetts Association of Councils on Aging (and memory café partners) is helping to expand the model in lower-income and non-white majority communities.
- Supporting the launch of over 100 cafés, the Percolator Memory Café Network is an incubator and technical assistance provider for anyone interested in starting or maintaining memory café operations. It’s also a resourced, collaborative network for peer learning and exchange. The Network offers quarterly meetings/webinars with presentations. The Networks’ Memory Café Toolkit is an excellent resource for planning and organizing café start-up and operations (Appendix, Table 5). A virtual café supplement to the Toolkit is now under development for release in 2021.
- The leadership of Beth Soltzberg, MSW/Jewish Family and Community Services and the Percolator Network have been key drivers of memory café proliferation statewide.
- The memory café movement is supported and promoted through additional partnerships with Dementia Friends Massachusetts, state agencies, the Massachusetts Executive Office of Elder Affairs, Alzheimer’s Association, and local foundations. Strong statewide support for age and dementia friendly communities provides financial resources for memory cafés and a receptive landscape for partnerships, in-kind donations, resources, services, and volunteers.

#### **In Wisconsin:**

- Start-up funding from the United Way, Rotary Club, a local community foundation, and dementia friendly community expansion funding from Bader Philanthropies helped build the Fox Valley Memory Project. Due to the pandemic, Fox Valley Memory Project now operates eight virtual memory cafés each month. It has provided support to people around the country seeking advice on how to pivot to this new type of memory cafe.
- The Library Memory Project (LMP) memory cafés span three counties in southeast Wisconsin. Major funding for this program is also provided by Bader Philanthropies. LMP partners with the Alzheimer’s Association of Southeast Wisconsin for operations support.
- The Wisconsin Dementia Resource Network is a collaboration of university and statewide partners that aim to share innovative best practice and resources related to ADRD. One of

their products is an excellent toolkit, Wisconsin Memory Cafés: A Best Practice Guide (Appendix, Table 5). In Wisconsin, the Fox Valley Memory Project and Wisconsin Dementia Resource Network play leadership, advocacy, and technical assistance roles similar to Massachusetts' Memory Café Percolator Network.

- Wisconsin's key memory café champion, advocate and thought leader is Susan McFadden, PhD.
- Wisconsin also has a resourced age and dementia friendly community movement statewide. These communities lift up the mission and purpose of memory cafés and lend a wide range of supports to café operations.

## Memory Cafés in Dementia, Age and Caregiver Friendly Communities

The goal of the dementia friendly movement is for individuals with ADRD to live well in communities that offer understanding and various forms of support for them and their care partners. By including more community stakeholders and normalizing aging and ADRD, people living with ADRD can continue to function and feel a sense of belonging in their communities and daily lives despite experiencing memory loss and other cognitive challenges. The presence of memory cafés and their continued operations and expansion advance these goals. Memory cafés invite participation from many sectors of a community – partners' involvement in cafés is visible and attainable. Cafés also provide information about other local support services and programs for persons with ADRD and their caregivers. Memory cafés are well positioned to advance ADRD, age, and caregiver-friendly community goals, and vice versa: these same communities foster memory café growth and success. As noted above, cafés can be an effective, relatively low-cost, easy-to-implement component of a strategy for communities to become ADRD friendly.

As discussed in previous sections, the memory café model's potential role in supporting age and dementia friendly communities is complemented by its additional role of potentially attracting other at-risk populations: older persons with early-stage ADRD, socially isolated older adults, adults in rural areas, and caregivers. The informal, drop-in, voluntary services that memory cafés provide make them an ideally accessible service, bringing in disparate populations that would experience similar health and psychosocial benefits. For example, targeting persons with early-stage ADRD and their families is a demonstrated way to grow memory cafés and build dementia friendly movements. The Alzheimer's Association's [Alz Meet Up](#) program specifically targets persons with early stage dementia.

An important memory café growth and sustainability opportunity is outreach to caregivers. Whether they are caring for someone with ADRD, caring for someone who may be socially isolated, or are themselves experiencing social isolation, caregivers can receive significant support from memory cafés. As noted above, cafes can offer a stimulating, enjoyable, away-from-the-home experience for caregivers together with their care recipients. Cafés also help caregivers take a break from caregiving, access peer support and social interaction—providing a form of respite. While memory cafés are well positioned to raise awareness about the role and challenges of caregiving for persons with ADRD at any stage, they may also be equally strong advocates for caregivers of socially isolated adults. Targeting caregivers for café outreach and programming and including them in efforts to build larger networks of cafés could be another key to memory café expansion.

Adaptations in café program delivery, marketing, or other attributes—such as offering online memory cafés, reaching out to non-ADRD audiences, and improving transportation support—may broaden the appeal of memory cafés to other older adult populations and caregivers, which will in turn have the effect of further encouraging café development and proliferation. The movement to build a broad-based coalition of memory café supporters requires a more capacious idea of who the target audiences are for memory cafés, as well as the strategies and operations that might be employed to enhance participants’ experiences. But memory cafés can potentially serve a role in educating those who have no obvious connection to ADRD, social isolation, or aging: younger community members, for example, and those who are unfamiliar with ADRD and the challenges that social isolation can present for less visible segments of the population. These individuals too may be targeted in outreach to promote awareness of or participation in memory café activities. The notion of memory cafés *servicing* communities is perhaps too limiting. In the end, memory cafés are meant to *build* communities, a movement based on inclusion and reflective of common values and the benefits of social supports regardless of individuals’ age, background, or health status.

## VIII. Appendix

**Table 1: Research and Literature on Memory Cafés for Persons with ADRD and their Caregivers**

Title	Topic
<i>Memory Cafés - General</i>	
<a href="#">Dementia cafés: Recommendations from interviews with informal carers</a>	Collection of recommendations based on interviews of family carers about their experiences of using the memory cafés
<a href="#">What Factors Predict Family Caregivers' Attendance at Dementia Cafés?</a>	Describes the demographic and psychosocial characteristics of caregivers who attend memory cafés, and identifies the factors that influence their attendance
<a href="#">Dementia cafés gaining acceptance around the globe</a>	Describes the growing popularity of memory cafés around the world, particularly in Japan
<i>Memory Cafés - Evaluation</i>	
<a href="#">A café on the premises of an aged care facility: more than just froth?</a>	Explores the benefits of memory cafés on residents of a large care facility along with their family and friends
<a href="#">Evaluation of Alzheimer's Australia Vic Memory Lane Cafés</a>	Survey and focus group-based evaluation of memory cafés in Victoria, Australia
<a href="#">A qualitative study of carers' experiences of dementia cafés: a place to feel supported and be yourself</a>	Interview-based assessment of care partners' experiences at memory cafés in London, England
<a href="#">A pilot memory café for people with Learning Disabilities and memory difficulties</a>	Assessment of a newly-opened memory café for participants with learning and memory difficulties
<a href="#">Dementia Cafés That Balance Programs, Guests Can Have Positive Impact</a>	Explores the appropriate balance between programs and guests



**Table 2: Research and Literature on the Effects of the Performing Arts on ADRD**

Title	Topic
<i>ADRD – Benefits of Performance Arts</i>	
<a href="#"><u>Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study.</u></a>	Evaluation of music-based intervention in improving quality of life and psycho-social health of persons with ADRD
<a href="#"><u>The Effects of Intuitive Movement Reembodiment on the Quality of Life of Older Adults With Dementia: A Pilot Study</u></a>	Explores the effects of an “intuitive movement reembodiment” program on the quality of life of older adults with dementia
<a href="#"><u>Creativity and dementia: does artistic activity affect well-being beyond the art class?</u></a>	Evaluation of the Alzheimer's Association's “Memories in the Making” art activity program in enhancing the well-being of individuals who are living with ADRD
<a href="#"><u>Artful Moments: A framework for successful engagement in an arts-based programme for persons in the middle to late stages of dementia</u></a>	A study of individuals with ADRD and their care partners who attended the “Artful Moments” program to determine if it facilitated positive engagement
<a href="#"><u>Observed well-being among individuals with dementia: Memories in the Making, an art program, versus other structured activity</u></a>	Assessment of individuals who engaged in “Memories in the Making,” an art program for persons in the early and middle stages of the disease that encourages self-expression through the visual arts
<a href="#"><u>The effect of folk recreation program in improving symptoms: a study of Chinese elder dementia patients</u></a>	Evaluation of the effects of a folk recreation program on the symptoms of people with dementia
<a href="#"><u>Visual Arts Education improves self-esteem for persons with dementia and reduces caregiver burden: A randomized controlled trial</u></a>	Studied the effects of a visual arts program where individuals with ADRD received instruction and produced a different type of artistic work each week
<a href="#"><u>Coffee, Cake &amp; Culture: Evaluation of an art for health programme for older people in the community</u></a>	Evaluation of an “art for health” initiative (“Coffee, Cake & Culture”) for older people living in a care home and a supported living facility
<a href="#"><u>"It makes me feel like myself": Person-centered versus traditional visual arts activities for people with dementia</u></a>	Assessment of individuals with ADRD’s wellbeing based on video data collected during a person-centered and intergenerational arts activity program called Opening Minds through Art in Ohio
<a href="#"><u>Towards a caring practice: reflections on the processes and components of arts-health practice</u></a>	Research case study of a 12-week visual art program in a nursing home with 10 participants
<a href="#"><u>Contributions of an artistic educational program for older people with early dementia: An exploratory qualitative study</u></a>	Qualitative study of a contemporary artistic educational program for older people with ADRD
<a href="#"><u>The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: a mixed-methods longitudinal investigation</u></a>	Evaluation of a 12-week visual arts program on people living with ADRD using a mixed-methods longitudinal investigation

<a href="#"><u>The development of Music in Dementia Assessment Scales (MiDAS)</u></a>	Study aimed at developing a robust music therapy outcome measure incorporating the values and views of people with dementia
<a href="#"><u>Comparative Efficacy of Interventions for Aggressive and Agitated Behaviors in Dementia</u></a>	Study examining the effects of massage and music therapy on reducing agitation and aggression among people with ADRD

**Table 3: Research and Literature on Social Isolation**

Title	Topic
<i>Social Isolation - General</i>	
<a href="#">Social Isolation Among Older Individuals: The Relationship to Mortality and Morbidity</a>	Information about social isolation, loneliness, and associated negative health outcomes
<a href="#">Loneliness: A disease?</a>	Explores the pathology of loneliness and its effects on individuals
<a href="#">The risks of social isolation</a>	Psychological study about the risk of loneliness and how to combat it
<a href="#">Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease</a>	Examines the effect of structured social support on caregivers
<a href="#">Loneliness and Social Isolation Linked to Serious Health Conditions</a>	Overview of the relationship between social isolation and negative health outcomes
<a href="#">Loneliness and Risk of Dementia</a>	A study testing the relationship between loneliness and the risk of dementia, as well as whether this association is independent of social isolation
<a href="#">Social Isolation, Loneliness, and Living Alone: Identifying the Risks for Public Health</a>	Examines the links between and common risks of living alone, being socially isolated, and feeling lonely
<a href="#">One is the deadliest number: the detrimental effects of social isolation on cerebrovascular diseases and cognition</a>	Review summarizing the relationship between isolation and mortality
<a href="#">Social Isolation and Loneliness in Older Adults</a>	Examines the association between social isolation and increased risk of ADRD
<a href="#">Caregiver Burden in Alzheimer's Disease Patients in Spain</a>	Analyzes the burden and problems borne by informal caregivers of patients who suffer from ADRD in Spain
<i>Social Isolation - Rural</i>	
<a href="#">The importance of emotional and social isolation to loneliness among very old rural adults</a>	Assesses the relative importance of social isolation to loneliness among older rural adults
<a href="#">Discriminators of loneliness among the rural elderly: Implications for intervention</a>	Examines predictors of loneliness among older rural adults
<a href="#">Geographical variation in dementia: systematic review with meta-analysis</a>	Analyzes geographical variation in dementia prevalence and incidence with special attention to rural areas
<a href="#">Rural-Urban differences in Alzheimer's disease and related disorders diagnostic prevalence in Kentucky and West Virginia</a>	Examines rural-urban differences in prevalence of ADRD among Medicare beneficiaries in Kentucky and West Virginia
<i>Social Isolation - Caregivers</i>	
<a href="#">Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers</a>	Documents the ways in which dementia care is different from other types of family caregiving and the effects of dementia care on caregivers
<a href="#">A broader view of family caregiving: effects of caregiving and caregiver conditions on</a>	Examines health and psychosocial outcomes of caregiving

<a href="#"><u>depressive symptoms, health, work, and social isolation</u></a>	
<a href="#"><u>Relationships between gender, age, family conditions, physical and mental health, and social isolation of elderly caregivers</u></a>	Investigates the relationship between caregivers' gender, age, family income, living arrangements and social support on social isolation and other outcomes
<a href="#"><u>A 2-year longitudinal study of depression among Alzheimer's caregivers</u></a>	Analysis of ADRD caregivers, social support, and prevalence of depression overtime

**Table 4: Research and Literature on Interventions Addressing Social Isolation**

Title	Topic
<i>General Interventions</i>	
<a href="#">How Local Interventions Can Build Capacity to Address Social Isolation in Dispersed Rural Communities: A Case Study from Northern Ireland</a>	Identifies pertinent issues related to rural communities and reviews an intervention aimed to encourage community cohesion
<a href="#">The effects of reminiscence therapy on psychological well-being, depression, and loneliness among the institutionalized aged</a>	Examine the effects of reminiscence therapy on psychological well-being, depression, and loneliness among institutionalized elderly people
<a href="#">Effects of Playing Wii on Well-Being in the Elderly: Physical Activity, Loneliness, and Mood</a>	Investigates the effects of compensatory strategies offered by Wii technology on physical activity, loneliness, and mood among older populations
<a href="#">Therapeutic effects of an indoor gardening programme for older people living in nursing homes</a>	Explores the activities of daily living and psychological well-being of older people living in a nursing homes, specifically the effectiveness of a gardening program in enhancing socialization and reducing loneliness
<i>Performing Arts Interventions</i>	
<a href="#">Music therapy as group singing improves Geriatric Depression Scale score and loneliness in institutionalized geriatric adults with mild depression: A randomized controlled study</a>	Evaluates the effect of group music therapy in the form of group singing, led by a music therapist, on depressive symptoms and loneliness in institutionalized geriatric individuals having mild depression
<a href="#">A Comparison of the Effects of Short-Term Singing, Exercise, and Discussion Group Activities on the Emotional State and Social Connectedness of Older Australians</a>	Looks at the effects of singing in alleviating social isolation among older populations.
<a href="#">The ice-breaker effect: singing mediates fast social bonding</a>	Compares singing and non-singing (crafts or creative writing) adult education classes over seven months in their effectiveness at encouraging social bonding
<a href="#">Cognitive, emotional, and social benefits of regular musical activities in early dementia: randomized controlled study</a>	Determines the efficacy of a music intervention based on coaching the caregivers of persons with ADRD to use either singing or music listening regularly as a part of everyday care
<a href="#">Translating Knowledge: Promoting Health Through Intergenerational Community Arts Programming</a>	Examines the benefits of creating and performing ensemble-created plays to older adults' and university students' well-being

**Table 5: Summary of Memory Café Toolkits and Resources**

Resource	Directory	Government Agency	Toolkit	Forum	Guide	Resource Hub	Membership Association
<a href="#">Memory Café Directory</a> : A directory of MCs provides an easy-to-use search tool for finding local memory cafés. Since the beginning of the COVID-19 pandemic, it has started listing virtual memory cafés. It also has toolkit-type information about starting and sustaining memory cafés.	X		X		X	X	
<a href="#">Percolator Memory Café Network</a> : A statewide mutual assistance forum for those starting and sustaining cafés created by the Jewish Family & Children’s Services. The Network collaborates with other organizations to make Memory Cafés more widely available in Massachusetts and beyond. Also includes <a href="#">information</a> about what a memory café is and isn’t.	X			X	X	X	
<a href="#">Alzheimer’s Cafés and Cousins</a> : A site that compares the evolving models of Alzheimer’s cafés and memory cafés and contains many practical suggestions for starting and running memory cafés.					X	X	
<a href="#">Dementia Adventure</a> : A guide to taking people living with ADRD on outings.					X	X	
<a href="#">Memory and Alzheimer’s Cafés in the UK</a> : A repository of memory cafés and other community programs for people with ADRD in the UK.	X					X	
<a href="#">Memory Café Catalyst</a> : An online community forum offering information and support for persons involved with memory cafés. The site includes a document in Spanish about memory cafés that was developed in Lawrence, MA.				X		X	
<a href="#">Rotarians Easing Problems of Dementia</a> : Rotary Clubs in England, which provided early leadership and support for memory cafés, published the original guide for setting up a memory café.	X				X	X	
<a href="#">Massachusetts Memory Café Toolkit</a> : A toolkit developed by Jewish Family & Children’s Services.			X		X		
<a href="#">Launching a Memory Café PowerPoint</a> : A PowerPoint deck detailing memory café resources and a toolkit for how to start a café.			X		X		
<a href="#">Wisconsin Memory Cafés</a> : A site with four best practice guides sponsored by the Wisconsin Dementia Resource Network, one of which is a toolkit about memory cafés.			X		X	X	
<a href="#">Wisconsin Alzheimer’s Institute</a> : A broad-based organization offering a clinical support network, research, and educational materials related to ADRD in the Wisconsin area.					X	X	

Resource	Directory	Government Agency	Toolkit	Forum	Guide	Resource Hub	Membership Association
<a href="#">Library Memory Project</a> : A partnership between public libraries in Waukesha, Washington, and Milwaukee Counties in Wisconsin to provide programs for people with ADRD.				X	X	X	
<a href="#">Fox Valley Memory Project</a> : Offers a variety of programs and services for individuals with ADRD with an emphasis on memory cafés.				X	X	X	
<a href="#">Neighborhood Memory Café Tool Kit</a> : Developed by Sydney Farrier, Pam Kovacs, Carole Larkin, and Pat Sneller, this toolkit contains practical advice for starting and sustaining a memory café.			X		X		
<a href="#">The Alzheimer's Café Toolkit</a> : This guide contains a practical information about starting and operating cafés. Also includes comments from a survey of 11 memory cafés around the country about what worked well and some problems encountered in operating memory cafés.			X		X		
<a href="#">Grantmakers in Aging</a> : A national membership organization of philanthropies that offers networking and resources related to older people and issues of aging.						X	X
<a href="#">Federal Administration for Community Living Funding</a> : Part of the Department of Health and Human Services, the agency funds services provided by networks of community-based organizations, and invests in research, education, and innovation related to the lives of older adults.		X				X	
<a href="#">American Society on Aging</a> : Association of nonprofits, businesses, and healthcare organizations working in the ADRD space.						X	X
<a href="#">Alzheimer's Association</a> : Leading ADRD advocacy group that offers resources related to ADRD care, support, research, and services on both national and local levels.						X	
<a href="#">AARP</a> : Association that disseminates research and resources on issues facing older adults.						X	X
<a href="#">Purple Angel Dementia Awareness Program</a> : Network of businesses, organizations, and public institutions that have trained their employees to offer hospitality and support to individuals with ADRD. The program offers training for entities to become designated as ADRD friendly. Operated through the Fox Valley Memory Project.	X					X	X
<a href="#">Dementia Friends</a> : Service that provides educational resources in order to train individuals and organizations to become more ADRD friendly.						X	

**Table 6: General References on Aging and ADRD**

Title	Description
<i>Aging</i>	
<a href="#">The US Population Is Aging</a>	Demographic information from the Urban Institute’s Program on Retirement Policy
<a href="#">The Population 65 Years and Older in the United States: 2016</a>	Demographic information from the United States Census’s American Community Survey Reports
<a href="#">Smaller Share of Women Ages 65 and Older Are Living Alone</a>	Trends about the share of the US population living alone
<i>ADRD</i>	
<a href="#">2020 Alzheimer’s Disease Facts and Figures</a>	Overview of ADRD landscape from the Alzheimer’s Association
<a href="#">NIH National Institute on Aging - Caregiving</a>	Health information for, research about, and news and evented related to caregivers
<a href="#">Caregiver Statistics: Demographics</a>	Definitions and data about caregivers including demographics