

Memory Café

TOOL KIT



Through the Dementia Friendly Engage Initiative, Dementia Friendly Dallas supports the development of Memory Cafés to encourage connection, engagement, and friendship for both the person living with dementia, and their care partners.

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INTRODUCTION

Memory Café guests say:

"I've made so many friends here. This is what we need - a place where we're treated like everybody else."

"Starting the day at the Memory Café just puts my husband in good spirits that carry through the day."

"It gives me an anchor to my week - a reason to get out of the house."

What is a Memory Café?

A memory café is a **social gathering for individuals living with dementia and their care partners**. Guests are welcome whose dementia is due to any underlying condition, and at any stage of disease progression. Care partners can include spouses, children, friends, and professional caregivers. Cafés meet in accessible community locations. They strive for an atmosphere that's more like a coffee house or a neighborhood party than a clinical program. Typically, guests are not asked for their diagnosis. This way, people who have not been diagnosed or are not comfortable with their diagnosis feel welcome. While information about resources and services is available for those who seek it, cafés provide a break from focusing on disease and disability.

Why are Memory Cafés needed?

People living with dementia, and their care partners, often become socially isolated. This is because dementia can make it hard to continue their everyday activities, but it's also because of stigma that makes people feel unwelcome or embarrassed when symptoms occur in public situations. For example, someone who was a devoted member of a faith community may stop participating because they are afraid that they won't be able to remember the names of people they've known for decades, or because friends at the congregation only talk to their spouse instead of speaking directly to them.

Most friends, neighbors and others in the community do continue to care about the person who has developed dementia. However, they may lack information about Alzheimer's and related disorders. They might not feel that they know how to interact with this person anymore. They may not realize that people living with dementia continue to need social connections just as much as

anyone else does. In the words of Tim Brennan, an advocate who lives with dementia, "We may have forgotten your name...but we remember love."

Medical and service providers might also make stigma worse without intending to. This can happen when providers call anyone living with dementia a "patient," even when this person is not in a medical setting. It can happen when the provider focuses on the diagnosis and doesn't consider the person's individual preferences and abilities. Sometimes when the media tries to emphasize that dementia is an urgent public health issue, or to show how difficult it can be to live with dementia, this message comes across in a way that scares people. When people feel overwhelmed by fear of dementia, this can add to stigma.

Unfortunately, the result is social isolation. Social isolation can make dementia symptoms worse, and it can also lead to many other health problems. The harder it is to live with dementia, the more the public is afraid of it. Fear and stigma go hand in hand and create a social environment in which many people are afraid to acknowledge their symptoms and seek medical evaluation.

In a survey of 2,500 people living with dementia in 54 countries, the 2012 World Alzheimer's Report found that

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

What Are the Benefits of Memory Cafés?

- Cafés are a cost-effective way to **support** both the person living with dementia and their care partners, such as a spouse, children, grandchildren, friends, professional caregivers, and so on.
- Because cafés are open to **people at any stage** of disease progression, many café guests are able to continue attending for months or years.
- For those who have not been diagnosed, or those who do not want to talk about their diagnosis, cafés offer a place to connect with others. Staff and volunteers will not ask guests if they have a diagnosis, and guests don't have to talk about dementia unless they wish to. Sometimes when people see that **life goes on with dementia**, they start to open up to more services.
- Cafés help guests **form new friendships**. Many people meet at cafés, enjoy seeing each other at each café session, and then exchange contact information and get together outside of the café.
- For care partners, cafés provide respite "with" the person who has dementia. They provide an opportunity to **have fun together**, not just to focus on problems and losses.
- Café staff and trained volunteers can **model effective ways to communicate** with those who live with dementia, and therefore offer a natural, low-key teaching opportunity to care partners.

- Many cafés involve creative arts, because people living with dementia can usually take part and enjoy these activities no matter how advanced their dementia is. Cafés can help care partners **learn creative activities** and techniques that they can do at home.
- Cafés offer a great **volunteer opportunity**. Volunteers help keep the cost of running a café manageable, and volunteers in turn have the opportunity to interact with people living with dementia in a positive, fun, strength-based environment.
- Cafés can bring in **participation from many sectors** of a community. For example, businesses can contribute food or sponsor a café. Local artists or musicians can facilitate activities. Students can volunteer.

Cafés can help communities become more “dementia friendly.”

Structure and Decision-making

The first Memory Café was started in 1997 in Holland, and the model has spread as a grassroots movement across many countries including the United States. No one “owns” the concept.

Each café is independently run and designed to fit its community. The [Memory Cafe Percolator Network](#) has developed a list of norms and standards entitled, “What a Memory Café Is and Isn’t.” While no one has the authority to enforce these standards, and cafés should be tailored to the unique needs of their community, coordinators of new cafés are urged to give these standards careful consideration. They were developed based on the experience of many cafés. Dementia Friendly Dallas has adopted these standards. (See **Appendix A** for more details about [What a Memory Café Is and Isn’t](#).)

HOW TO START & SUSTAIN A MEMORY CAFÉ

There are many details to consider when starting a Memory Café. We have created a [Memory Cafe Planning Worksheet](#) which is available in **Appendix B**.

Where to Hold It

This is often the first decision to make when starting a café. Cafés have been held in libraries, museums, restaurants or coffee shops, historical societies, senior centers, community centers, outdoor gardens, houses of worship, bowling alleys and many other locations. All locations have their pros and cons.

When choosing a location there are some “must haves,” and some “pluses” that are nice but not essential.

Must Haves

- Fully accessible building, including accessible restrooms
- Sufficient parking
- Accessible via public transit if many guests, staff or volunteers will use this means of travel
- Generally convenient location for guests, staff, and volunteers

Pluses

- Free, or nominal fee to use the space
- Available indefinitely
- Family restroom
- Kitchen access for easier food preparation/clean up
- Appealing & inviting location with a community feel

Also consider **how the location is viewed** by your community. If you are holding your café in a senior center, for example, will people with younger onset dementia hesitate to come? If you are holding it in a house of worship, how best can you welcome those from other faith traditions? (Of course, a residence or congregation may want to have a café just for its members and not open to the public, and this is also fine.)

Assuming that you want to reach out to a wide spectrum of community members, you might consider asking organizations or businesses associated with those you'd like to reach to be **cosponsors or promotional partners**. A cosponsor typically is involved in programmatic decision-making, and may also contribute funds or in-kind resources. A promotional partner has a more limited role. A promotional partner lets you use their name/logo, and agrees to share your flyer with their client list.

Whenever setting up cosponsor or promotional partner arrangements, put the terms in writing. The name that you give to the arrangement (i.e., "cosponsor," "promotional partner," or something else) doesn't really matter – what matters is that you clearly define what you will do and what the other party will do. In particular, be aware that some potential collaborators may wish to market their services to your café guests, and that you will need to **set clear boundaries** so that guests do not receive unwanted solicitations.

You can also use room decorations, background music, and the choice of activities strategically to **set the tone you want**. For example, a café held in a medical or social service provider's building could use extra decorative touches like tablecloths and LED candles to make the setting feel more like a café, and less clinical.

Who Should Participate

Next, think about the guests whom you hope to serve. In your community, there may be many different groups of people who could benefit from participating. Inclusivity is a core value of the memory café movement.

When you start a new program, you have to **build trust and connections** with the people whom you want to serve. Dementia is hard for many people to talk about, and many members of the public have never heard of memory cafés, so this step of the process is very important and it takes some time.

Surveys of Memory Café participants have found that **word of mouth** is the way that most people learn about memory cafés and decide to attend. The time you spend to engage community members and build interest for your café will pay off when you see people coming in your door to attend your café!

During your planning process, **reach out** to community groups such as veterans' organizations, cultural groups, faith communities, disability services providers, etc, as well as individuals who are community leaders. Talk with them about the idea of a memory café and ask for their input. Their suggestions may make your café more accessible and welcoming, and their involvement may encourage them to support and participate in the café.

Partnerships with other service providers can be very helpful in making your café welcoming to different groups of people. For example, many cafés have been developed to serve guests with both dementia and a developmental disability, as well as people with just dementia. Many of these cafés were launched by a partnership between an aging services provider and a disability services provider. These café coordinators have reported that it took time and flexibility to bring these two groups of service providers together, but that they have made a lot of progress and their café guests are benefiting.

In addition to inclusive cafés, there is also a benefit to memory cafés that are tailored to a particular community. For example, in your community there may be a need for memory cafés that are held in Spanish, Vietnamese, Hindi, Korean, or Tagalog. The music, decorations, refreshments, activities and other features of these cafés make them feel like home to the guests whom they serve.

Referral Sources

On an ongoing basis, you will need to communicate with a broader circle of referral sources to share your flyer and other information about your café. Build an email mailing list as you go. **Invite professionals** to come to your café so that they can see what it's like. Remember that cafés are an unfamiliar model, and professionals may hesitate to refer people to your café until they see a café in action. (However, let them know that your rule for visitors is full participation! They'll get more out of the visit that way, and guests won't feel that they are being "observed." Professional visitors may be accustomed to models where there is a distance between service provider and service recipient, so they may not jump in unless they are given this guidance. Visitors tend to have a great time, and truly appreciate your invitation to participate!)

When someone who attends your Memory Café, who was referred by someone else, be sure to thank the referral source! A list of **Frequently Asked Questions (or FAQs)** can be useful to referral sources. (See **Appendix C** for a [FAQ Template](#) you can use.)

In your FAQs, make sure to explain that guests who require help with personal care (such as ambulating, eating, and using the restroom) must bring someone with them. This could be a friend or family member, or a professional caregiver. It's important to let your guests and referral sources know this clearly. Staff and volunteers who do not have the proper training should not be asked to provide personal care. By making your rules and resources clear in advance, guests who need assistance will have it, and everyone can be safe and comfortable.

Another key piece of information to include in your FAQs is a statement about participation from Assisted Living or Memory Care Residences and Day Programs. It's a good idea to require that these providers contact the café coordinator before they bring a group to the café. Some cafés welcome groups; others do not. Because **Memory Cafés are person-centered**, it would not be appropriate for a community to bring a large group of their residents to your Memory Café. Attendees should be individually selected, and each participant should have a care partner in attendance.

Volunteers

Volunteers offer a double benefit to cafés. First, they provide assistance with the tasks of running the café and ensure that everyone will have someone to talk to. (This is particularly important for drop-in cafés, where the number of guests coming on a given day is uncertain.) Second, volunteers get to see individuals living with dementia in a joyful, strength-based environment. They get to know café guests, and this often transforms their views about living with dementia. Volunteers then go back out into their community with the understanding that people living with

dementia are unique individuals who have a lot to contribute, and this attitude helps to reduce social stigma.

You can find volunteers for your café in many places. Some cafés partner with college sororities or clubs. Others bring in high school or middle school students. (Take advantage of community service requirements that many schools have!) Some cafés held at a senior center or residence recruit older adults in that community who do not have dementia to become café volunteers. With a little training, anyone with a reasonably outgoing personality can do a wonderful job.

You can also put out a call for volunteers through your town Facebook group, or the Neighbors App. You can also list your need for volunteers on [JustServe.org](https://www.justserve.org/). However, it can be a bit easier to work with groups of volunteers who have a central contact person to help you with any paperwork needed for new volunteers, give you a list of who is coming to each session, arrange transportation, etc.

The single best question to ask of prospective volunteers is this: "Volunteering at a memory café is like hosting a party. Would you enjoy this?" Some volunteers prefer concrete tasks and less social interaction, and this may not be the right volunteer role for them. While your volunteers will help with specific tasks, such as name tags, registration, and hanging up coats, their most critical role is to welcome guests and mingle.

Training needs will depend upon the experience that your volunteers come in with. Volunteers can become a **Dementia Friend** online or via an hour-long public awareness session provided by **Dementia Friendly Dallas**. Go to <https://dfdallas.org/> to register to attend a Dementia Friend Session.

When to Hold It

Some cafés meet in the morning, and some in the afternoon, some on weekdays and some on weekends. Early evening cafés could be ideal for individuals who are working during the day. The day and time will definitely affect who attends your café; however, there is no day/time that will work for everyone.

Consider what works best for the space, the café coordinator and other staff, your prospective guests and your prospective volunteers. In all of your decisions, consider sustainability. For example, maybe volunteers will be willing to help out on a weekend once in a while, but not on an ongoing basis. Or maybe the weekend is best, because you won't be competing to use the space with weekday programs.

You don't want to compete with other cafés that meet at the same time or even during the same week. Keep in mind that some guests will attend several cafés if their schedules don't conflict. As one woman who attends several cafés with her husband puts it, they have become "café groupies."

What to Do at Your Café

What you do at your café tends to flow from the decisions you've made up until now – where, who and when. Below are some basic guidelines and ideas. However, cafés around the country have found that the original plan almost always needs to evolve. Get feedback from guests over the first few months, tweak things, and get more feedback!

Depending upon your group, guests may want lots of planned activity, or none at all. They may prefer specific types of activities, and dislike others. It's best not to invest lots of resources in particular activities until you make sure these are what your guests really want to do. Make sure not to overschedule your café. People living with dementia often benefit from a slower pace and relaxed environment. **Keep your plans simple** and let everyone take their time.

Most cafés start with relaxed socializing, then have some kind of planned activity, and then end with more social time. The planned activity may take up about half of the café time. Examples include a facilitated activity led by a guest artist, exercise and movement, lectures, garden walks, and adventure outings. Outings tend to be quite expensive, so make sure you have the resources to sustain this, or perhaps limit them to a couple of times per year.

Many cafés involve the creative arts, such as music, dance, poetry, visual arts, and art education.

Benefits of creative arts include:

- Guests can participate and be challenged no matter their cognitive abilities. There are no wrong answers.
- Engaging in the creative arts levels the playing field between guests with dementia and their care partners. In fact, care partners may be inhibited and hesitant to try something, while those with dementia may be able to "plunge right in."
- The creative arts put us in touch with our shared humanity, and can help guests feel connected to one another.
- You can encourage guests to try these activities at home, perhaps by talking as a group about how to do so, and offering a take-home handout.

Cafés tend to find that a **high level of participation by guests** is critical to the success of any planned activity. To encourage participation, consider having guests move into a circle of chairs for the planned activity. If you invite a guest artist, let this person know that you don't want them to

perform, but rather to facilitate a participatory activity. If they have not worked with people with dementia, they may need to brainstorm with you about possible ways to increase participation by café guests.

If you invite a **guest artist or facilitator**, you'll need to decide whether to offer payment. You may find several people in your personal or professional circle with hidden talents who are delighted to facilitate a session for free. There are also some wonderful teaching artists who do this for their living and need to get paid. You may find business sponsors willing to cover a guest artist's honorarium a few times per year. A facilitator's guide to help you communicate with potential guest artists can be found in **Appendix D: [Memory Café Guest Artist Guide Template](#)**.

Older adults in general and people living with dementia in particular may be on the alert for activities or a facilitation style that makes them feel they are being treated like children. (They've had bad experiences with this!) Beware of activities that appear like children's crafts, or facilitation styles that talk down to people. The best facilitators have a style that could be termed "dignified playfulness." They encourage guests to explore and even be silly, but within a context of mutual respect and acknowledgement that we are all adults. It can help if they begin by sharing some information about the traditions and cultural context of a particular activity.

Some cafés send out information ahead of time about the activity that is planned at their café. Others just announce the café dates. We have heard instances in which guests opted out because they didn't like the sound of the activity. And, we've heard from guests who want to know the activity in advance, because it helps them motivate their care partner with dementia to attend. So, your decision may be based on resources and your work flow.

Again, some cafés never have guest facilitators, or only rarely. Some find that guests really just want to socialize. Or, they may have simple activities that café coordinators can facilitate themselves, like listening to music, sharing holiday recipes or photos, or telling favorite jokes.

How to Sustain Your Café

Now that you've decided where to hold your café, who you'd like to involve, when to hold it, and what to do there, it's time to figure out HOW to set it up, get the word out, and pay for it!

Room Setup

A well-designed café helps guests living with dementia to feel safe, confident, and successful. This in turn provides a wonderful respite experience for care partners, who are able to take a deep

breath and relax, chat with others, and enjoy seeing their partner having a good time. The following are some design elements to consider:

- **Clear signage**, with pictures as well as words when possible (to indicate the location of the café room, food and coffee, and restrooms)
- **Sufficient lighting**
- **Clear pathways** to prevent falls
- **Background music** kept to a soft level, so as not to distract or inhibit conversation
- Also limit the number of people per table, to **reduce noise** and stimulation level
- **Decorations** to make the environment festive. Some ideas: LED candles, silk flowers, tablecloths. Artwork produced at the café can be used as decorations
- **Conversation prompts** on the tables to help guests and volunteers mingle. Include photos as well as words, and avoid questions that require short-term memory

This list of suggested items has been compiled by several cafés. You may want to hold off on expensive items or large quantities until you get a feel for what your café guests like to do. (A [Suggested List of Items to Purchase for a New Memory Café](#) is available in **Appendix E**)

Registration Process

You'll need a check-in area for guests arriving at the café. It's always good to keep things simple, but at a minimum you'll need name tags, and a way for people to join your email and text notification list. You will probably also want to have a photo/video release form, and a donation can for those who wish to pitch in. (A [Picture and Video Image Release Template](#) is available in **Appendix F**)

Communication: Outreach

Outreach is one of the **biggest challenges** for new cafés. Most people haven't heard of memory cafés, and social stigma often keeps people isolated from services and hesitant to reach out. Therefore, potential guests may have to hear about the café three or four times before they give it a try. Expect it to take at least **six months to build your attendance**. Because most conditions causing dementia are progressive, you will find that over time many of your regular guests will become unable to attend due to disease progression. Outreach will be an ongoing process, though once you have steady attendance, word of mouth will help bring in new guests.

Once your Memory Café is up and running, you can list it on the **Dementia Friendly Dallas Community Calendar** (<https://dfdallas.org/dementia-friendly-at-work-calendar/>), and on the Alzheimer's Association & AARP Community Resource Finder (<https://www.communityresourcefinder.org/>).

Consider collaborating with other cafés in your region to support each other's outreach efforts. Some cafés have created regional calendars that list all of their meeting times and locations on a single flyer.

Communication: Keeping in Touch

Once you've worked hard to build your attendance, you certainly want to **keep in touch**. Start a list of providers to whom you can send a reminder before each café session. If you send them a flyer, ask them to post it and share it with individuals whom they think could benefit.

Develop some kind of registration form so that you can add guests to your mailing list. You'll want to send an email, a text message, or both, to remind guests of upcoming café sessions. When deciding what information to request on your registration form, keep in mind that you will want to evaluate the impact of your café, as discussed below. There may be demographic information you'd like to collect at registration and then refer to later when you are evaluating your café.

Again, cafés typically do NOT ask guests for a diagnosis, or whether they are a person living with dementia or a care partner. This is very important, because some people will not want to come to a café if they are asked if they have a diagnosis. Some cafés keep track of overall numbers by creating a field in their computer database for the staff person's observation of their role (person with dementia or care partner).

(A [Memory Café Mailing List Registration Form Template](#) is available in **Appendix G**)

Communication: Odds and Ends

As you think about how to keep in touch with guests, you may consider whether or not to require an **RSVP**. Most cafés find that whether they request or require an RSVP or not, some guests who'd intended to come will not, because despite planning, dementia means that sometimes it's just not a good day for an activity. And, some guests will show up without an RSVP. That said, cafés with limited space or complex planned activities will need to require an RSVP, and should make this very clear in their flyers and announcements.

Also keep in mind that you may occasionally need to cancel due to weather or other emergencies. Cafés that have a firm RSVP policy will have an easier time contacting those who had planned to attend. In most cases, you will need several ways to let attendees know that the café has been canceled – phone calls, texts, email messages, and a recording on the contact person's voice mail. It's a good idea to write up a brief "Weather/Emergency Cancellation Process" handout to make available for your guests that lets them know how they'll find out if there's a cancellation.

Some guests who attend your café will want to contact one another. Making new friends is a wonderful benefit of cafés, but you should encourage participants to share their contact information directly, so that you can respect their privacy

.

Finances: Costs

One of the benefits of memory cafés is that they serve both people living with dementia and care partners at a modest expense. For most cafés, the coordinator's time is the largest expense. The least expensive cafés are held at restaurants or coffee shops, so that guests purchase their own food. For those starting a café with grant funding, it's important to keep costs sustainable from the start, so that the program can be sustained when grant funding runs out.

Most cafés cost between \$8,000 and \$15,000 annually, with an additional \$2,500 - \$4,000 in start-up expenses. These estimates include the coordinator's salary, which is the biggest cost. If your Memory Café is strictly volunteer run, your expenses will be much less. A SAMPLE [Memory Café Budget](#) is available in **Appendix H**)

Finances: Revenue

Memory cafés have been successful in gaining support from many community businesses and organizations. Options include seeking in-kind contributions, for example of food or art supplies. In addition, many cafés seek financial sponsorships. Sponsorships can be for one session only, though a seasonal or multi-session sponsorship gives you more support and a more efficient process. It's wonderful when a representative from the sponsoring business or organization attends the café to participate and soak up the atmosphere. It can be a joyful and eye-opening experience that can encourage their interest in broader dementia-friendly business practices and community efforts.

It's critical to put the terms of a business sponsorship on paper. While engaging the business community can help sustain cafés and also raise awareness in the business community, you want to ensure that your guests do not feel marketed to during cafés. This template can be used to design a handout for potential business sponsors. Tailor the specifics to your café, but do make sure to include clear information about your expectations and how you will acknowledge the sponsor. (**A [Memory Café Sponsor Guide Template](#)** is available in **Appendix I**)

Despite your best intentions, you may find that representatives from private businesses come to the café and hand out business cards or try to talk with guests about their business. Having the written sponsor guide available can help you to gently take them aside and let them know that unsolicited marketing is against café policy. If they want to support the café and get recognition for this, they are welcome to become a sponsor.

In addition to business sponsorships, you could create a system for **tribute or memorial sponsorships**. This could be a nice way for the care partner of someone who has died or can no longer participate to say thank you, and stay connected to the café. It could be a great birthday gift for a café regular, to whom everyone can sing "happy birthday" at the sponsored session. You may want to offer honorary or memorial sponsorships at a flexible rate, for those who really would like to sponsor but cannot afford a given fee.

Unrestricted donations for your café may be available through town clubs and other sources. Rotary International has been a key supporter of cafés in the UK. Most towns have additional clubs, too. A town cultural council may support a guest artist honorarium. Though this is not likely to bring in much money, it is a good idea to have a donation can for guests who wish to chip in.

No matter who supports your café or how they do it, make sure to thank and acknowledge them. Ways this can be done include a thank you letter, a sign on your registration table, verbally announcing their support during the café, a social media post, and an end-of-year list thanking all supporters, which you might include in a café mailing.

Finally, some cafés elsewhere in the country have run on a fee basis. These tend to be cafés with expensive activities, such as outings. One café in San Francisco started on a fee basis, and then after a year or so was able to get corporate donations and to stop charging a fee. It is also possible to charge a fee on a sliding scale so that those who can pay do, and no one is prevented from participating due to resources.

EVALUATION: HOW TO IMPROVE

Evaluation starts at the beginning, so think ahead. If you have funders, consider their requirements, plus what you would like to learn in order to improve your café. Plan to conduct a simple annual evaluation even if it's not required by funders or your organization.

Perhaps the simplest approach is a written survey. It's great to survey staff and volunteers as well as guests. If you have the resources, conduct a few follow-up interviews with guests who are willing to have an in-depth conversation with you. The few in-depth interviews combined with your survey data will give you a lot of important information to improve your café. (A [Memory Café Evaluation Template](#) is available in **Appendix J**)

For in-depth interviews, consider these questions:

- How does attending the memory café affect you?
- Have you been able to meet people at the café whom you enjoy seeing at café sessions?

- Have you met anyone at the café whom you have gotten together with?
- Does participating in the café have an impact on your relationship with your care partner?
- Have you tried any of the café activities at home?
- If you could wave a magic wand and change anything about the café, what would it be?

TIPS FOR INCLUSIVE AND SPECIALIZED CAFÉS

Memory cafés: the spirit of inclusion

Memory cafés developed to respond to the social isolation experienced by many people living with dementia and their care partners. Because of this goal, inclusiveness is at the heart of memory cafés. Another way to say this is that a welcoming, friendly atmosphere is what really matters most at a memory café. It matters more than how nice the room looks, or how tasty the food is. People who find their way to a memory café want to feel that they are accepted there and that they belong.

Dementia affects people from every walk of life. So, many café coordinators wonder how to make their café welcoming to people whose needs and backgrounds are so varied.

As Mr. Rogers used to say, “who are the people in your neighborhood?” That’s a great question to ask, because there might be specific steps you can take to make your café welcoming and accessible to everyone “in your neighborhood.”

Below, you will find some guidance about serving people with hearing loss, younger onset dementia, and intellectual/developmental disabilities. You will also read about serving members of the LGBTQIA+ community, and about culture/language specific memory cafés.

These are just a few of the life experiences that may affect what someone needs from a memory café. And of course, many people will identify with more than one of these life experiences; they are not mutually exclusive! We look forward to ongoing learning about great ways to address community needs at memory cafés. Our goal: memory cafés for all!

Serving People With Hearing Loss

An estimated 30% of people aged 60 and older live with hearing loss. By the time people reach their 70s, this percentage climbs to 60%.

There are several connections between dementia and hearing loss. Some medical conditions, like high blood pressure, increase the risk of both dementia and hearing loss. Research shows that difficulty hearing might increase a person's risk for developing dementia or it might make the dementia progress more quickly. Also, sometimes it is hard to know whether a person's difficulties are caused by hearing loss, dementia, or both. Finally, there is a lot of social stigma about both dementia and hearing loss.

Memory café coordinators should be aware that they are already serving a lot of people with hearing loss. In many ways, cafés are perfect environments for people with hearing loss. Some care partners who have hearing loss but not dementia have told us that the relaxed pace and accepting atmosphere at memory cafés has helped them a lot! However, memory cafés are social environments and there can be a lot of background noise.

- The **acoustics** of your meeting space will make a huge difference. Wall-to-wall carpet, window curtains, and a lower ceiling with acoustical tiles can help. Be careful about noise from other activities happening nearby. Use a private meeting room, and close the door (at least partially) if possible.
 - Have a **quieter area** available for people who are uncomfortable with the level of background noise in the room, and might want to sit and talk in twos or threes.
 - Use a **microphone**, even if you think you are loud enough without it! When others in the group make comments, give them a microphone to speak into, or repeat what they said so that the whole group can hear it.
 - **Introduce the topic** you are talking about. Context helps people follow what you are saying, even if they have trouble hearing you.
 - **Speak clearly**, and not too fast. Use facial expressions and gestures to reinforce what you are saying.
 - Make sure that **everyone can see you**. Are you facing the group? Is there enough light to see your face?
 - If someone has had trouble hearing you, take the time to **repeat or rephrase** what you said. Don't say "never mind" – the person wants to communicate with you!
 - Don't ask, "Can everybody hear me?" at the beginning. The people who CAN hear will call out, "yes!" and everyone else will be quiet! Instead, ask people to raise their hand if they have trouble hearing at any point, or if they need you to slow down.
 - Consider making **assistive listening devices** available. There are many different kinds, so consult with a municipal agency or community organization that focuses on accessibility.
- Many of these are excellent tips for communicating with anyone who lives with dementia, too!

Keep in mind that people who have been deaf since childhood may identify as culturally Deaf. These individuals will probably have different needs than someone whose hearing declined later in life. Deaf culture is the set of social beliefs, behaviors, art, literary traditions, history, values, and shared institutions of communities that are influenced by deafness and which use sign languages as the main means of communication.

Serving People With Younger Onset Dementia

According to data from the [Health and Retirement Survey](#), there may be as many as 500,000 Americans under age 65 living with cognitive impairment or dementia. Getting an accurate diagnosis of the brain conditions that cause dementia is a challenge for people at any age. However, it can be even harder for younger people to get an accurate diagnosis, because dementia is not expected in someone younger.

It may be a harder choice for younger people to attend their first memory café. Café coordinators need to be aware that younger people may assume that this program is not for them. Some tips: use photos showing people of varied ages, seek volunteers of varied ages, and choose music and activities that would appeal to a wider age range. Cafés held in a senior center or a residence may need to make an extra effort to balance the perception of their location as a place for older people only. Once younger people do come to the café for the first time, what will make them want to come back is the sense of being welcomed and included.

Serving Members of the LGBTQIA+ Community

LGBTQIA+ is a term describing a large and diverse group of people based on their sexual orientation or gender identity: lesbian, gay, bisexual, transgender, queer, intersex, asexual/ally. The terms that people use to describe themselves are changing and evolving over time. The "+" is meant to include other terms that some people may prefer and that are not captured by the LGBTQIA letters.

LGBTQIA+ people are part of every cultural community. While their experiences are extremely varied, there are some common threads that memory café coordinators should be aware of. LGBTQIA+ adults are at higher risk for some health conditions associated with dementia, such as high blood pressure, heart disease and diabetes. They often face misunderstanding and stigma, sometimes from their own family members and other important personal networks, such as a faith community. This can lead to **social isolation**, making the isolation that sometimes comes with dementia and dementia caregiving even worse

LGBTQIA+ adults may hesitate to seek support or services, because they are concerned that care providers will have a **lack of awareness or prejudice**. An example of inclusive language is *"This inclusive program is fully accessible and open to all members of the community. We warmly invite members of the LGBTQIA+ community who may feel especially isolated when supporting loved ones with Alzheimer's or other forms of dementia."*

In addition to outreach efforts and inclusive, welcoming language, it is important to be on the lookout for ways that your café might inadvertently make people from the LGBTQIA+ community feel unwelcome. Some examples are: using photos of only male-female couples, providing activities and supplies based on gender stereotypes (cooking for women; woodworking for men), using forms that list "husband & wife" instead of "spouse or partner".

People who may bear a double or triple burden of stigma and exclusion are harder to reach, and quite naturally they may hesitate to come to a memory café. But this is not because they would not benefit from the café. On the contrary, these are folks who are dealing with tremendous challenges, and the café could make a huge difference for them. Once they do come to your café, you want to do all you can to help them feel: "Yes, I belong here!"

Serving People with Intellectual or Developmental Disabilities (IDD) in addition to Dementia

Intellectual & developmental disabilities are disorders that are usually present at birth and that affect physical, intellectual, and/or emotional development. Many of these conditions affect multiple body parts or systems. Some examples are Down syndrome, cerebral palsy, and autism spectrum disorders. People with IDD comprise about 3% of the global population.

People with IDD are living longer than in the past, which means that their risk of developing dementia during the course of their lives is increasing. In general, people with IDD have the same risk of developing dementia as the population at large, except for people with Down syndrome. People with Down syndrome have about a 60% risk of developing Alzheimer's, with an average age of onset around age 52 – 53. For people with Traumatic Brain Injury, the risk of developing dementia is about 2.3 – 4.5 times greater than for the population at large.

Memory cafés strive to be "stigma-free" spaces, and they are designed for people with a range of cognitive needs. So integrating individuals with IDD and dementia with individuals without IDD and dementia would be, in the words of one of the café coordinators, "a natural fit."

In addition, inclusivity is one of the core values of memory cafés. People with IDD are among the “people in our neighborhoods.” People with IDD who have developed dementia should have access to memory cafés.

IDD-inclusive cafés report that the great majority of café guests accept and support one another. There have been some instances in which a guest from the general population seemed uncomfortable with a guest with IDD, but this has been rare.

However, cafés do find it is important to maintain a balance of populations so that the café “feels” like home to everyone.

Some tips from IDD-inclusive Memory Café Facilitators:

- Building relationships with other care providers is necessary and it takes time. Open and honest communication is essential. Building these relationships is also rewarding!
- Make sure that all providers understand the philosophy and structure of the café, so that they can make appropriate referrals and can arrange for professional caregivers to attend as needed. Again, open communication is the key.
- Group homes and day programs serving people with IDD may not have enough staff to send one-on-one help with each café guest. However, not every guest needs this much help. Take a person-centered approach, and communicate openly.
- Guests with IDD are more likely to attend with professional caregivers rather than family members. Professional caregivers and family members have different needs, though both groups can benefit from attending memory cafés.
- Remember that friends and housemates with IDD may be the care partners for some café guests.

Here are some quotes from coordinators of IDD-inclusive memory cafés:

Culture or Language-specific Memory Cafés

You have just read about ways to make memory cafés inclusive of people with different needs and backgrounds. If many people who live “in your neighborhood” share a particular language or culture, you may want to hold the café in that language and flavor it with cultural elements that will make it feel like home to these individuals.

Culture or language-specific cafés are especially important because of additional barriers to getting support that some groups of people face. These barriers may make it harder for some individuals who are dealing with the challenges of dementia to find out about your café, to get there, and to trust that they will be welcomed. While people of every background develop dementia, some groups have higher risk and less access to services.

For more information, take a look a look at the health equity or disparities web pages of these organizations:

- Alzheimer's Association: <https://www.alz.org/professionals/public-health/issues/health-equity>
- US Against Alzheimer's: <https://www.usagainstalzhaimers.org/learn/disparities>
- Alzheimer's Disease Disparities Engagement Network: <https://alzheimersdisparities.org/insights/>

One way that many communities cope resiliently against discrimination is to develop community places and organizations that are safe and supportive. These may be religious congregations, restaurants, or a barber shop. These might be great places to hold a memory café.

Note: The Memory Café Toolkit is also available in Spanish at www.jfcsboston.org/GuiaCafeDeMemoria. A recorded webinar in Spanish about starting a Spanish-speaking memory café is available on the same page as the Spanish Toolkit and on the Percolator webpage at www.jfcsboston.org/Percolator.

Other groups to consider

The information you have just read is based on the experience of many memory cafés that are working to provide services to many different groups of people. There are so many more stories waiting to be told!

Here are some other “people in your neighborhood” whom you may want to consider:

1. **Veterans** may be more likely to attend cafés if you reach out to them through local veterans' organizations, and ask about the type of activities that might interest them.
2. **“Men's sheds”** started in Australia and have spread to many countries. Their slogan is “Men don't talk face to face, they talk shoulder to shoulder,” so it is better to work on a project together than to sit and talk. This is a generalization, of course, but it rings true for some individuals. Café coordinators may want to look up “men's sheds” to get ideas about hands-on activities that could be incorporated into memory cafés.
3. **Sports fans!** “Football cafés” developed in England. The guests enjoy a football game (what we in the U.S. call soccer) at the stadium together. This is part of a trend in England, of cafés that meet in public spaces. As the dementia friendly community movement moves forward here in the U.S., we hope that the level of public awareness and understanding about dementia will grow. Perhaps we will see a similar trend here, as public spaces may become more accessible to people living with dementia.
4. **Faith communities** are important in the lives of many people who develop dementia. For many people, dementia causes people to ask spiritual questions about the meaning of a person's life

beyond their cognitive abilities, and how to sustain hope and strength during difficult times. Houses of worship that host or participate in memory cafés can offer familiar hymns or prayers to help people with some of these needs.

5. **Different generations** can come together at memory cafés. Young volunteers, or young family members can add a refreshing element to memory cafés. Research shows that meaningful, positive contact with people living with dementia reduces stigma. So, when young people take part in memory cafés, their concept of dementia changes, and they are able to use their awareness to help make our communities more dementia-friendly!



Memory Café

Norms and Standards

Adapted from the Greater Boston Memory Café Percolator

A Memory Café is:

- A **friendly meeting place** for adults living with mild cognitive impairment or dementia, and their care partners, where they can relax, have fun, and meet others. A diagnosis of dementia is not required to attend.
- A **social gathering** where individuals living with dementia and their care partners can share enjoyable experiences.
- Structured to **support and engage** individuals with a range of cognitive abilities by focusing on the participants strengths and interests.
- Managed by **Dementia Friends volunteers**, and based on the characteristics and needs of the community it serves.
- A program that strives to be **welcoming, inclusive, accessible, supportive, and safe** to participants with diverse backgrounds and experiences.
- **Free of charge**, or open to those who cannot afford a fee.

A Memory Café is NOT:

- A facilitated support group, workshop, seminar or lecture.
- A drop off respite program.
- Responsible for providing personal care or other assistance.
- A marketing opportunity for a commercial enterprise.



Memory Café

Planning Worksheet

Adapted from the Greater Boston Memory Café Percolator

WHO | WHAT | WHERE | WHY | WHEN | HOW

WHO

Who should attend:

Possible volunteers:

Referral sources & community partners:

Name ideas:

Other factors:



Memory Café

Planning Worksheet

Adapted from the Greater Boston Memory Café Percolator

WHO | **WHAT** | WHERE | WHY | WHEN | HOW

WHAT

Activities that may interest participants:

Participants' strengths & interests:

Community Resources:

Models to follow:

Budget considerations:

dfdallas.org



Memory Café

Planning Worksheet

Adapted from the Greater Boston Memory Café Percolator

WHO | WHAT | **WHERE** | WHY | WHEN | HOW

WHERE

Potential locations should be free, convenient, & wheelchair accessible, with ample parking, and should be available on an ongoing basis.

Evaluate the pros and cons of each location, including how it will be viewed by potential participants and volunteers.

Option 1:

Option 2:

Option 3:

Offsite alternatives:



Memory Café

Planning Worksheet

Adapted from the Greater Boston Memory Café Percolator

WHO | WHAT | WHERE | **WHY** | **WHEN** | HOW

WHY

Why is a memory café needed in your area?

Why should people participate?

Describe your goals & how success will be measured.

WHEN

Time of day, day of week, frequency & duration?

Volunteer commitments (training, frequency)

dfdallas.org



Memory Café

Planning Worksheet

Adapted from the Greater Boston Memory Café Percolator

WHO | WHAT | WHERE | WHY | WHEN | **HOW**

HOW

Calendar of Events/Themes:

Budget (initial, growth, ongoing):

Funding & In-kind support for materials, refreshments, promotion, etc.:

Publicity/Referrals:

Communication:

dfdallas.org

_____ **Memory Cafe**

[Location] | [Contact information]

Frequently Asked Questions

Q: Do participants need to acknowledge that they have dementia?

A: No. Participants will not be asked if they have a diagnosis. The environment is geared to the comfort and success of people with a wide range of cognitive capacities. The focus is socializing and creative exploration - activities common to all of us.

Q: What disease stage is the Memory Café geared to?

A: The Memory Café is appropriate for anyone who enjoys being with a group of people, can negotiate the wheelchair accessible physical space, and is self-sufficient with personal care needs. A care partner also attends and participates. Volunteers will NOT be able to provide personal care assistance.

Q: Is the Memory Café for care partners, too?

A: Yes! Memory Cafés give care partners a chance to meet and socialize with other care partners, while enjoying social activities with their loved-one.

Q: Will you offer informational speakers at the Memory Café?

A: No. We want to give people living with cognitive impairment a break from focusing on memory and recall, and we welcome those who have not been diagnosed or do not acknowledge their diagnosis.

Q: Is there a charge to attend the Memory Café?

A: No. We do not charge a fee to attend the Memory Café. Donations to help offset the cost of supplies and refreshments are welcomed.

Q: Do I have to RSVP ahead of time in order to attend?

A: You are not required to register or RSVP, however it is recommended so we can ensure we have enough supplies and refreshments available. We understand that living with dementia can be unpredictable, so unscheduled attendance or unplanned absences are expected.

Q: What takes place during the Memory Café?

A: [Describe your schedule and activities. If you offer structured activities, you may wish to note that no experience is necessary.]

_____ **Memory Café Guest Artist/Activity Facilitator Guide**

We are delighted that you are interested in sharing your skills with us. Creativity and interpersonal connection are basic human needs that endure or even grow stronger in people living with dementia.

We ask guest artists/activity facilitators to share a little of what they do, and then to facilitate a **participatory** activity. A memory café is not a performance space; participation by the guests is the key to a meaningful and fun experience for everyone.

Tips

- Think of ways to get guests participating and interacting, whether it be through movement, discussion, singing, making visual art, etc. Talk with the café coordinator about what guests might enjoy.
- If you do not have experience working with people who live with dementia, please attend a Dementia Friends Session online or in-person. You can register to attend at <https://dfdallas.org/>.
- Guests may be sensitive to feeling that they are being talked down to, or treated as children. It can be challenging to introduce activities that many have not participated in since they were children. Talking a little about the tradition or cultural context of the art form or activity helps to set a dignified tone. Treating each person as an adult and with respect is essential.
- Simplify instructions by breaking tasks down into simple steps. The final outcome is less important than the enjoyment of the process.
- Avoid raising the topic of dementia unless guests do. Not everyone has been diagnosed or accepts their diagnosis.
- Let volunteers and staff know how they can help you, for example, by passing out items, or jumping in to participate if guests seem hesitant.

Logistics

The _____Memory Café usually meets on [day/time]. We ask the guest artist/facilitator to arrive by [time].

We [are/are not] able to offer an honorarium [standard amount/amount to be determined].

The typical schedule at _____Memory Café is:

[time volunteers arrive]

[time guests arrive]

[social time]

[structured activity]

[closing time]

Thank you again for your interest in the _____Memory Café! For more information, please contact _____ at _____.



Supplies can be sourced through donations, thrifting, lending or purchase.

- Cafe signage
- Paper/ink/printing for sign in sheets, handouts, volunteer training materials, etc.
- Name tags & markers
- Tablecloths & paper goods
- Table decor & seasonal decorations
- Art supplies
- Refreshments
- Music playlist (from your phone)
- Large format and/or large print books (borrow from the library)

Memory Café Photo/Video Image Release Form

By signing this release form, I authorize _____ Memory Cafe (The Memory Café), to use the following personal information:

- (1) My picture – including photographic, motion picture, and electronic (video) images.
- (2) My voice – including sound and video recordings.

I hereby grant to _____ Memory Café, the right to use, publish, and reproduce, for all purposes, my name, pictures of me in film or electronic (video) form, sound and video recordings of my voice, and printed and electronic copy of the information described in sections (1) and (2) above in any and all media including, without limitation, cable and broadcast television and the Internet, and for exhibition, distribution, promotion, advertising, sale, press conferences, meetings, hearings, educational conferences and in brochures and other print media. This permission extends to all languages, media, formats and markets now known or hereafter devised. This permission shall continue perpetuity.

I further grant The Memory Café all right, title, and interest that I may have in all finished pictures, negatives, reproductions, and copies of the original print, and further grant The Memory Café the right to give, sell, transfer, and exhibit the print in copies or facsimiles thereof, for marketing, communications, or advertising purposes, as it deems fit.

I hereby waive the right to receive any payment for signing this release and waive the right to receive any payment for use of any of the material described above for any of the purposes authorized by this release. I also waive any right to inspect or approve finished photographs, audio, video, multimedia, or advertising recordings and copy or printed matter or computer generated scanned image and other electronic media that may be used in conjunction therewith or to approve the eventual use that it might be applied.

I acknowledge that I have read the foregoing and I fully understand the contents.

IN WITNESS WHEREOF, I have executed this release on this ____ day of _____, 20__.

Print Name:

Telephone Number:

Address:

City/State/Zip:

Signature:

Welcome!

Memory Café Registration Form

Your Name:		Preferred Name:	
Address:			DOB:
City:	State:	Zip:	
Email Address:			
Cell Phone:		Home Phone:	
Permission to Contact (for reminders/cancellation)	<input type="checkbox"/> Email	<input type="checkbox"/> Phone/Text	
Allergies:			<input type="checkbox"/> No Allergies
In Case of Emergency			
Name:		Relationship:	
Cell Phone:		Home Phone:	
Email Address:			
How did you hear about our Memory Cafe?		<input type="checkbox"/> Word of Mouth	<input type="checkbox"/> Flyer
<input type="checkbox"/> Agency or Organization (specify)	<input type="checkbox"/> Facebook	<input type="checkbox"/> Alz. Assoc.	
<input type="checkbox"/> Healthcare Professional (specify)	<input type="checkbox"/> Dementia Friendly Dallas		
Is there anything else you would like us to know?			

We are so glad you are here!

Appendix H: SAMPLE Memory Café Budget ([DOWNLOAD](#))

Sample Memory Café Budget

START-UP EXPENSES		Total
Approximately 50 - 100 hours of program coordinator's time		
Decorations for café ambience (typically \$100 - \$250)		
Necessary items: name tags, table cloths, paper goods.		
Optional: LED candles, vases/silk flowers, Café sign, reusable serving plates.		
Total start-up expenses		0.00

ONGOING PROGRAM EXPENSES	Per Session	Annual
Program coordinator (approx. 20 hours per café session)		
Guest Artist or Performer honoraria		
Art or Craft Supplies		
Outreach/Publicity (flyers, ads)		
Refreshments		
Photocopying/printing		
Decorations		
Fee for use of space		
Outings		
Other expenses:		
Total ongoing expenses (subtotal + overhead)	\$0.00	\$0.00

PROGRAM INCOME	Per Session	Annual
Donations from Memory Café guests		
In-kind support (food, other items)		
Other income (grants, in-honor-of gifts)		
Business sponsorships		
Total income	\$0.00	\$0.00

[Name of Café] Sponsorship Opportunities

[Logo/location etc]

Who we are

The _____ Memory Café opened its doors in _____. This is a relaxed social gathering held monthly, free of charge and open to anyone affected by memory loss or related cognitive changes. The _____ Memory Café is designed to make people living with dementia feel comfortable and successful. For care partners, the Café is a much-needed break and a chance to have fun together without focusing on the disease. [Quote from a café guest, if you have one.]

Sponsorship opportunity

The _____ Memory Café welcomes community support so that it can continue to be offered free of charge to participants. A [\$ amount] sponsorship covers refreshments and an honorarium for the guest artist for one session. The sponsor is welcome to choose a particular café session to sponsor, and we welcome sponsorships that cover several sessions. [Option: you could list a menu of fees to support one session, a season, a year, etc.]

In recognition, we will post acknowledgments thanking the sponsor at the registration table and the refreshment table. We will also announce the sponsorship at the beginning of the café. The sponsor may bring brochures to place on the resource table, and a staff person is welcome to attend. We ask that individuals who visit the café not market their services to guests during the café. [Tailor this section to your café. It's very important to clearly state what the sponsor will receive for their donation, and any specific boundaries that you would like them to respect.]

Other ways to support the _____ Memory Café

- Volunteer
- Learn about dementia (ask us how)!
- Come visit! You're welcome to experience the _____ Memory Café first hand.

Contact

For information or to arrange a sponsorship, please contact _____ at [phone/email].

Appendix J: Memory Café Evaluation Template ([DOWNLOAD](#))

Dear _____Memory Café Guest,

Please take a few moments to share your ideas and suggestions about the _____Memory Café. Your responses will help us to improve this program. Your responses are anonymous unless you choose to share your name at the end of the survey.

1. How many times have you attended the _____Memory Café? Please check one response below:

☐ 1 – 2 times ☐ 3 – 4 times ☐ 5 or more times

2. Please circle one response for each statement below to indicate how IMPORTANT this aspect of the café is to you:

Aspects of the Memory Café:	UnImportant (1) Very Important (10)									
	1	2	3	4	5	6	7	8	9	10
Convenient Location										
Warm Welcome										
Meeting New People										
Creative Activities										
Fitness Activities										
Other Activities										
Refreshments										
Attending with a friend/family member										
Other:										

3. What do you like best about the _____Memory Café? _____

4. What could we do to improve the _____Memory Café? _____

5. The _____Memory Café activities that I LIKED best are: _____

6. The _____Memory Café activities that I DID NOT LIKE are: _____

7. Please let us know of any ways that we could help guests to meet and get to know other people at the _____Memory Café.

Alternative or additional questions:

- Do you feel like you are a part of the Memory Café?
- Have you talked with other Memory Café guests?
- Do you feel like you belong?

8. Does coming to the _____Memory Café affect the rest of your day or week?

[] Yes

[] No

If YES, please describe the impact that coming to the_____Memory Café has.

9. Would you be interested in participating in a brief follow up conversation so that we can learn more? If so, please provide your contact information below.

Name: _____ Phone #: _____

Thank you for your feedback. If you have questions, please contact _____ at [phone/email].