

MEMORY CAFÉ GUIDE TO LEADERSHIP AND OTHER MEANINGFUL ROLES FOR PEOPLE LIVING WITH DEMENTIA

Brought to you by the *Living Well with Dementia at the Café* initiative,
a collaboration between the JF&CS Memory Café Percolator and
Dementia Action Alliance

“People living with dementia want to learn
how to live well with dementia.”

– Laurie Scherrer, Advocate, Board Member
of the Dementia Action Alliance, and
Blogger at dementiadaze.com



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Virtual JF&CS Memory Cafe, March 2021

How this guide was developed

Since 2014, the JF&CS Memory Café Percolator (the “Percolator”) has supported the proliferation of high-quality memory and Alzheimer’s cafés by helping a growing international network of cafés to share resources, ideas and mutual support. Dementia Action Alliance (DAA) is a national nonprofit advocacy and educational organization creating a better society in which individuals and families can live fully with dementia.

Acknowledgements

The Percolator and DAA began to develop the “Living Well with Dementia at the Café” initiative in winter 2020, to bring together the Percolator’s network of cafés with DAA’s network of advocates living with dementia. This guide was developed with participation by the Percolator Dementia Inclusive Work Group, comprised of Mike Belleville, Michael White, Gail Sonnesso, and Beth Soltzberg. It is informed by a survey of café coordinators and a panel discussion held at the Percolator idea exchange on December 8, 2021, during which many café coordinators provided insights and suggestions, including Beverley Cassidy, Emily Williams, Brian Connolly, Rob Griesel, Erika Campbell, and Shelly Roy.

For more information about this guide, please contact Beth Soltzberg at bsoltzberg@jfcsboston.org or 781-693-5628, or visit the Percolator at www.jfcsboston.org/Percolator

The two goals of this guide

As part of the global dementia friendly movement, memory cafés are guided by the principle, “nothing about us without us.” This means that people living with dementia and their care partners should help design and run memory cafés. Currently, stigma about dementia often complicates this goal.

The first Alzheimer’s Café was launched in 1997 by Dutch geriatric psychiatrist Dr. Bere Miesen, in Leiden, Holland. It aimed to break the silence and offer open discussion about dementia. Dr. Miesen recognized that fear prevented many people from seeking a diagnosis and getting support from others. He said, “I personally find it a sort of ritual for getting rid of your fear. We all know that tragedy is not deep and sharp if it can be shared with friends.” (Miesen, 2010)



Dr. Miesen’s model spread through many parts of Europe, Canada and Australia. Some of the “European model” cafés offer a combination of information and sharing about dementia, social

time and entertainment. Some include a public health nurse, and can offer a diagnostic screening right at the café. In 2008, Dr. Jytte Lokvig and Lori La Bey started the first US cafés.

Most cafés in the US have taken a somewhat different path from the “European model.” Most focus on socializing and “leaving the disease at the door” rather than providing information and discussion about dementia. In the United States, more cafés use the term “memory café” rather than “Alzheimer’s café,” both in recognition not everyone living with dementia has Alzheimer’s disease, and to make the café more inviting to people who have strong negative reactions to the concept of “Alzheimer’s” or “dementia.”

The reality is that stigma about dementia pervades our society. And stigma and lack of awareness contribute to social isolation, which may be as hard to live with as the symptoms of dementia.

“Stigmas about dementia can build massive walls that can prevent us from having as fulfilled of a life as possible. Stigmas rob me of living my life to its fullest with dementia.”

- Alexander (Sandy) Halperin, DDS, Advocate

To serve as a welcoming place for participants who have not been diagnosed or who are not comfortable with their diagnosis, many cafés do not ask participants what their diagnosis is or if they have one. Cafés are often careful to avoid the terms “dementia” or even “memory” in their program name and their outreach materials. Information about resources and services is available for those who seek it, but cafés provide a break from focusing on disease and disability. Café coordinators don’t always know which of our participants are living with dementia – and that’s by design.

This approach makes cafés accessible to people who do not accept their diagnosis. For these individuals, and their care partners, cafés may be a lifeline. And, this approach keeps the café’s focus on sparking joy and a sense of community.

“It gives me a feeling of home.”

- Memory Café Participant

But this approach also has a cost. Are we accepting stigma as a fixed fact of life? Instead, could cafés help to break the silence and stigma about dementia, and model how people can live well with dementia?

“Dementia does not define who I am. It is merely a small part of the many facets of my life, affecting decisions and changes in how I live. Living with dementia does not mean total memory loss, inability to make our own decisions, nor undeserving of living an independent life enriched with purpose, joy and fulfillment.”

-Laurie Scherrer, Advocate

Our challenge is this: Can we meet both goals?

Can we keep our cafés inclusive and welcoming, while also making inroads against stigma and showing that living well with dementia is possible? How do we continue to meet each of our participants “where they are” with regard to how open they, as individuals, are about dementia? The Percolator and DAA developed this guide to help memory cafes explore and strive for both of these goals.

Most memory cafés run on a small budget and have limited staff/volunteer time. We appreciate that some of these ideas require an investment of time, and we encourage you to move forward at a sustainable pace. Thank you for all that you do to make our world more welcoming and inclusive!

Approaches to meeting both goals

1. Reduce stigma by sharing the voice of people living well with dementia

General principles

Stigma about dementia permeates our society. We can find stigma in every corner of our communities, including service and medical providers, the media, faith communities, families and individuals who themselves are living with dementia. Stigma limits what people feel is possible, for themselves and others.

“Diagnosis has changed our world forever. Our lives become limited by the stigma we face in the world around us. It’s like we have a target painted on our foreheads shouting out ‘dementing’ for all the world to see. People become awkward in our presence, are unsure of our behaviour, and our world becomes circumscribed by the stigma of our illness.”

- Christine Bryden, Dementia Activist quoted in [World Alzheimer’s Report 2019](#)

Café coordinators often don’t raise the topic of dementia, so that the café is a comfortable place for people who have not been diagnosed or are not comfortable with their diagnosis. However, many participants can benefit from the opportunity to talk or learn about dementia.

Often the most powerful way to reduce stigma and learn about how to live fully with dementia is to hear directly from people living with dementia.

Always “meet each participant where they are” with regard to their openness about dementia. One participant may talk openly about their symptoms and want to share ideas, while another participant may say that they do not have dementia. The coordinator or facilitator’s role is to make sure that each participant feels welcome and respected.

Specific ideas

- Consider conversation starters that may open up conversation about dementia, but do not require people to talk about dementia, such as: What are some of the challenges of life these days? What changes do you see in your life or health? What frustrates you?
- Normalize cognitive changes: “Is anyone else sometimes forgetful or confused about things that happen?” If you’ve had experiences of cognitive changes, share your own experiences to normalize this.
- Offer a “tips and strategies” time. Participants could talk about tips regarding dementia symptoms, or anything else.
- If one of your café participants is very open about their diagnosis and feels comfortable sharing their experience publicly, you could ask them to lead or share during the “tips and strategies” time. For example, would the participant want to share how they felt when they told friends or family that they are living with dementia?

Important: Make sure that the participant understands that some café participants do not acknowledge that they have dementia, and chat in advance about what they would like to share to make sure that it is likely to be received well. This groundwork will promote a positive experience for both for the person who is sharing, and for the other participants.

- Dementia Action Alliance is working with the Percolator to offer “Café Chats: Living Well with Dementia.” This is a short virtual presentation by a person living with dementia about living fully with dementia. This talk is usually about 10 minutes in length. There may be a fee. Please contact Karen Love, Executive Director, Dementia Action Alliance, at karenlove4@verizon.net for more information.

2. Involve café participants in planning and design

General principles

Café coordinators have voiced concerns about challenges that may arise when involving participants in planning, design and carrying out activities at cafés. Specific participants may not attend consistently, and therefore cannot be counted on for particular tasks. Other participants may get very involved and then need to step back, due to the progression of dementia. Finally, anyone who has ever managed volunteers knows that sometimes having others “help” can be more work than doing the job yourself!

These challenges are all real, and café coordinators need to be realistic about their time and resources, and proceed in a way that will be manageable and sustainable. However, despite the challenges it is worth looking for ways to involve participants more. Volunteering is about more than getting the work done; it is also a way to share meaningful roles and purpose, create a sense of ownership of a program, foster communication and deeper connections. These roles can provide a great deal of value to the individuals whom we aim to serve. We can also learn a great deal from our participants when they have the opportunity to truly share with us.

Most people living with dementia want and need a purpose! There is little motivation to get out of bed if you have no purpose to do things. This can be as simple as walking the dog throughout the day or mentoring someone else living with dementia. Everyone needs to feel purposeful and needed.

If we approach this process with flexibility, back-up plans, clear communication and realistic expectations, we will maximize the benefits and minimize the stresses!

Café coordinators have also said that they don't want to burden people living with dementia and their care partners with these tasks. Certainly, some participants do not want to be involved with planning or helping. However, some participants say that helping is very meaningful to them.

"Keep in mind the value of feeling a sense of purpose. Even a small task, like handing out pencils, gives the person a sense of importance and belonging."

– Laurie Scherrer, Advocate

Café coordinators and participants say that you have to actually ask your participants to get involved – don't assume that they realize that there is an opportunity to do more unless you say it! Likewise, often people want to help – but they don't know how. They need specific information about what they can do.

Treat each person as an individual. Do not assume that a person living with dementia needs a care partner to participate with them, and vice versa.

Specific ideas

- Establish an advisory board or planning committee for your café, and continuously invite café participants to join. These meetings can be short and informal, and they provide an opportunity for input and feedback, and to identify interests and skills that café participants would like to share.
- Have a sharing time during each café gathering. Invite your participants to bring poems, quotes, stories, art work, memorabilia, etcetera, to share with the group. (This works particularly well with virtual cafés, because participants can just grab something they have in their home – they don't need to plan ahead to bring it.) Based on this sharing, identify participants who would like to facilitate an activity for the group.
- If you are part of a network of cafés or looking to expand to other areas or additional activities, engage café participants as seed members for new café programs.
- Cafés often have a hard time getting the word out. Ask participants to be your ambassadors: to post flyers, share announcements on social media, make an announcement at their club or faith community, and directly invite others whom they know. Designate a “bring a friend” week or month. (Thanks to Morgen Hartford for this idea.)

Encourage sharing by being prepared with a flyer that participants can post and a file they can share on Facebook and other social media. Recognize that sometimes people want to help, but they don't know how to make a flyer or a social media post. Simplify the process and offer help as needed.

- Ask for help and participation during the café – handing items out, sharing a story, sitting with a new participant or (for a virtual café) telling new participants what the café is like. This does not require advance planning or a firm commitment to prepare for the café or even attend the particular café gathering.

How to recruit and support people living with dementia in a planning or advisory role

- Try to identify individual passions, and be willing to “roll with them”!
- Each café will be different –let local interests flourish!

- Provide clear information about your café's goals, values, and the tasks that are expected. Provide written and verbal instructions.
- Consider piloting this process with one or two people to start, to make sure that you have time to fully support them.

How to make sure that these roles are meaningful and not “token” roles

- Provide clarity, support, and a role that actually helps the café. It does not have to be a big or complex role, but it should not be “busy work.”
- For example, maybe some café participants could take turns being a “host” or “welcome committee,” and sit with newcomers to the café. This makes a meaningful contribution to creating a welcoming environment.

3. Create individualized roles for specific participants

General principles

Personalities and talents vary! Some of your participants might like to be song leaders or joke tellers, while others would never dream of this, but would be glad to help in a quieter way.

If dementia symptoms, transportation, or other barriers might prevent the person from attending when they'd planned to lead an activity, have a back-up plan for that café gathering.

Don't consider it trivial to hand things out during the café, or help with other logistical tasks. Any role that actually helps the café is meaningful, and it gives participants a chance to contribute and participate.

Specific ideas

- A friendly, caring or sociable participant can volunteer as a greeter, to welcome participants as they come in. If the café is virtual, and if this person is comfortable using the chat function or unmuting themselves, they could agree to post messages in the chat or give a brief verbal hello to welcome everyone, and to welcome new people. This could be planned in advance.
- Be creative and flexible in thinking about ways to help, taking advantage of individual interests. One café has a participant who shops for decorations and decorates the café. The sky is the limit.

- For participants who enjoy sharing something, think about potentially taking it one step further. For example, there's a café that has a participant who likes to share poetry. The coordinator is currently encouraging him to consider leading a creative writing project where all café participants could share their thoughts to create a piece of their own or a group piece.

"One of our care partners has taught yoga before. I finally got around to asking if she would lead a session for the café, and she was delighted! I'd been worried that she would see this as a burden. I offered her the same honorarium I usually give our teaching artists. I think that our participants will be excited and supportive of 'one of their own' leading the session."

– Memory Café coordinator

"One of our former caregivers whose wife died with dementia was a master gardener. He presented a program at one of our memory cafés."

– Memory Café coordinator

- Talk in detail ahead of time with your participant who is offering a program, to make sure that they understand the café's goals and that they have the support to do this successfully. Ask them if they need support, such as reminders. They may want to write out what they want to say and run it by you in advance, so that you could give them feedback and then be able to prompt them if they get stuck. Have a backup plan in case the day of the gathering turns out not to be a good day.

“I strive to appoint each participant based on their strengths to shine for others in a leadership capacity by learning as much of their history and subject matter expertise as possible.”

– Erika Campbell, Memory Café Coordinator

Some participants expect high-quality, polished programming, which makes it hard to have other participants volunteer to lead activities. How to balance this?

- Every café is different. Some will truly love “do-it-yourself” activities, and others will prefer programs by professionals.
- Offer short segments, where participants read a poem, tell a joke, share a talent, etc – without asking them to lead an hour-long program if they are not experienced at this.

“Set your participants’ expectations! Don’t bill it as ‘Broadway’ if it’s going to be ‘Off-Broadway!’”

– Mike Belleville, Advocate

4. Encourage interaction among participants

Ideas that work for in-person, virtual and hybrid cafés

- Begin the café gathering each time with a welcome and simple introduction, so that everyone knows the purpose of group and any ground rules.
- Encourage conversation among participants, not just between the facilitator and participants. This may require adjustments to your technology or facilitation style,

particularly for a hybrid (in-person/virtual) café where it can be harder for the two groups of participants to interact.

- “Match make” participants who might want to connect outside the café, by introducing them.
- Establish an “opt in” process for those who would like to share their contact information. Consider including a photo of each person on the contact sheet.

Ideas for an in-person café gathering

- Seating arrangements matter! Small tables promotes small group interaction, whereas a larger circle helps people interact with the facilitator and each other during a group activity. If you have enough space, you could have both arrangements, and ask people to move into the circle during a facilitated activity.

“Don’t hesitate to ask people to move into a circle, even if it seems inconvenient. You will simply get more interaction when everyone is together and can see each other’s faces.”

– Memory Café coordinator

- There is benefit to people sitting with others whom they know, and benefit to sitting with new people. Just make sure that new participants are welcomed and included.
- Be aware of acoustics and background noise. Too much noise makes it hard for people living with dementia to process information, and many participants additionally have impaired hearing. Consider eliminating background music, especially music with lyrics. Arrange seating to minimize background noise. Use a microphone whenever possible. See the in-person Memory Café Toolkit for more information about serving people with hearing loss at the café: www.jfcsboston.org/MemoryCafeToolkit
- Pair participants who are living with dementia, or “care pairs,” to work on an activity or project together.
- Allow time after the café for participants to sit and chat, exchange contact info, etcetera.

Ideas for a virtual café gathering

- Take advantage of everyone being at home by having participants bring “show and tell” items.
- If your participants are very tech-savvy and you have enough volunteers to distribute among each room, consider dividing into virtual breakout rooms with a prompt, such as an evocative photo to discuss, to help people get to know each other and talk to one another more.

5. Get feedback from your participants to help guide your café

- Cafes can conduct formal feedback surveys periodically, and can also request informal feedback at the end of every café gathering or frequently. For example, the coordinator can ask participants at the end of each gathering for new discussion topics or activity suggestions.
- Observe participants’ response to different activities. Ask volunteers for feedback on their observations as well.

“We’ve relied on the file cards more than anything else! We leave the cards and markers on tables, and ask if /they’d like to volunteer, be on our board, present something, or what topics or themes they be interested in. We’ve gotten a lot of really interesting suggestions.”

– Beverley Cassidy, Memory Café coordinator

- See the in-person Memory Café Toolkit for more information on feedback and evaluation: www.ifcsboston.org/MemoryCafeToolkit

6. Support advocacy beyond the café

Supporting advocacy beyond the café may be more feasible for some cafés than others. Each café does not have to be all things to all people. Some organizations that provide cafés offer

multiple services, have more staff, and advocacy is a more natural and feasible role. However, these ideas are worth considering for all.

- One café engages its participants to share their experience at [Dementia Friends](#) information sessions in the community.
- The [Dementia Action Alliance](#) offers three weekly virtual discussion groups for people living with dementia and a Monday-Friday virtual engagement program (sessions include music, poetry, trivia, dance, meditation and others). These can be great opportunities for café participants to get support, meet others living well with dementia, and learn about advocacy opportunities. All programs are free.
- One café has shared poems and crafts made by participants at exhibits outside of the café. (Two organizations that have refined ways to publicly present creative work made by people living with dementia and care partners are [TimeSlips](#) and [Opening Minds through Art](#). You would need to contact the organization to learn more about their guidance and resources.)
- Another cafe is for residents of a retirement community (500+ people), and it is billed as for people with memory challenges and all allies (spouses, friends, family, paid caregivers, etc.) to build a dementia-friendly community.

“We involve participants in planning and contributing to our Age/Dementia Friendly City. We address important issues in our city and hold City Hall meetings with our city officials. We also cross generations with our local University on events happening in our city. For example, we just celebrated our "Senior Homecoming". Our participants were in a parade and a Sock Hop to follow.”

– Memory Café coordinator

“We involve participants in planning and contributing to our Age/Dementia Friendly City.”

– Shelly Roy, Memory Café Coordinator

Resources

1. Dementia Action Alliance
 - Words Matter guide: <https://daanow.org/wp-content/uploads/2020/05/WORDS-MATTER-Revisions.pdf>
 - Many other resources: visit www.daanow.org
2. JF&CS Memory Café Percolator: www.jfcsboston.org/Percolator
 - Percolator Memory Café Toolkit and virtual/hybrid supplement: www.jfcsboston.org/MemoryCafeToolkit
 - Percolator idea exchange with Dementia Action Alliance, December 8, 2021: discussion of meaningful roles that people living with dementia can take to help shape and lead memory cafes. See the [recording](#) and [slides](#) from the meeting.
3. Act on Alzheimer’s guide to organizing and conducting focus groups for people living with memory loss and for family caregivers: <https://actonalz.org/sites/default/files/documents/ACT%20Focus%20Group%20Guidelines.pdf>.
4. National Council of Dementia Minds: <https://dementiaminds.org/>
5. Dementia Alliance International: <https://www.dementiaallianceinternational.org/resources/>
6. Dementia Friendly America –toolkit for dementia-friendly communities, inclusion and leadership of people living with dementia: <https://www.dfamerica.org/inclusion-and-leadership-of-people-living-with-dementia>
7. Reimagining Dementia: A Creative Coalition for Justice: <https://www.reimaginingdementia.com/>

“I learned not to worry about being the entertainment, being the manager, being the leader – I had to let that go. Once I started sharing the lead, it worked extremely well, in fact our group started to grow.”

– Brian Connolly, Memory Café Coordinator