Reinventing the Memory Café

Creating Connections in a Physically Distant World

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This presentation will cover

• What a memory café is, and how it dovetails with other social engagement programs
• Transitioning to a virtual format or starting a new virtual café
• Resources for starting or further developing your own café
Caveat

• We are still in a time of transition
• Most photos in this presentation show in-person cafes!
What is a Memory Café?
Key ingredients

* Welcoming atmosphere * Focus on social connection
* Designed for care partners AND people living with dementia
Key ingredients

* Any stage, any underlying condition
* No one is asked their diagnosis
* Tailored to local interests, language, needs
Why do Alzheimer’s/Memory Cafés exist?

“All of our friends disappeared.”
The need is GREATER now

• Reduced access to activities and social support
• Greater feeling of isolation

USAgainstAlzheimer’s A-List survey, March 25-30, 2020, n=807;
https://www.usagainstalzheimers.org/sites/default/files/2020-04/a-list_pulse_coronavirus_4.30.20_0.pdf
Common Threads

• Any social/creative engagement programs for people living with dementia and their care partners

• Any strength-based activities that aspire to help people live well with dementia
The Virtual World: what it means for us
Loss and growth can happen at once
Losses

• Stressed organizations are faced with re-making their programs
• Some staff and some participants lack hardware, WiFi, comfort with tech
• Tech annoyances and challenges
• Some, not all, people with advanced dementia find virtual programs confusing or disengaging
COVID-19 has reduced equity

- Disproportionate disease burden in communities where people must continue to work in person, live in tight quarters, have less access to culturally/linguistically appropriate care

- Digital divide has become an even more critical barrier
Growth and Opportunities

- Virtual programs are **more** accessible for some participants
- No need to get up and out of the house
- No travel, parking
- Can attend from any location (increases language access; family members can attend together from afar)
- Less expensive to run (no food, limited need for supplies)
Don’t underestimate the power of virtual connection!

VIRTUAL MEMORY CAFES

Dementiamentors.org
What will the future hold?

Can we maintain the gains when someday we are able to meet in person again?
Virtual Memory
Cafés
The lay of the land since COVID-19 began…

- Massachusetts had over 120 cafés
- 12 have closed
- Several others are on hiatus
- 25 are now meeting virtually
- 3-5 are now meeting outside
Is it possible to START as a virtual café?

- Yes!
- Most had funding/some of the plans in place before the pandemic
- Many of the considerations are the same, so you can learn from toolkits developed for in-person cafés
What’s different?

- Need to consider digital accessibility for both staff and café guests

- Decide: will we transition to a physical space when we are able to?

- Decide: how locally-focused do we want to be?
How to meet virtually?

• Most meet on Zoom

• Other platforms: GoToMeeting, Facebook Live, BlueJeans, Webex

• Suggestion: Use the platform that is familiar and supported by your organization. If starting from scratch, use Zoom.
Consider offering a phone option

• Choose more auditory activities, or plan ahead to provide images/supplies. (Adds expense)

• “Narrate” for those on the phone
Phone only

Gary Glazner, Founder and Executive Director, Alzheimer’s Poetry Project, runs 30 minute Poetry Parties over the phone

- Visit www.alzpoetry.com
- Contact: garyglaznerpoet@gmail.com
When to hold your café

• Choose timing that’s sustainable for café providers; morning is best for some guests, afternoon for others
• Evening may be best for employed care partners
• Consider the schedule of nearby cafés
• Many are providing shorter, more frequent online cafés
Let’s talk about outreach and inclusivity
Four challenges to publicizing your cafe

• Most people don’t talk openly about dementia
• Most people aren’t familiar with memory cafés
• Many of the people who you want to reach have become isolated
• Technology is a barrier to virtual participation for some potential participants
Publicizing a virtual cafe

• Build a list of providers willing to receive and share your café announcements
• Article in local paper
• PSA on town cable TV station
• Facebook and other social media
• Organizational website
• Council on aging, faith community newsletter
• Library calendar
• Email blast to prospective families
• Outreach to residential communities; including residential staff on planning team
• Presentations to community groups
• Outreach to support groups
• Automated phone calls
• Direct mail
• Outreach to other memory cafés
• Insert in monthly bill for adult day program
• Encourage people to attend with friends – it’s a great way for friends to stay connected

Main change since COVID-19: not posting physical flyers on bulletin boards, at resource fairs
Kickoff event

• Hold an education event that will attract people beyond potential café guests
  – Example: Dementia Friends information session
• Use some of the time to introduce the café concept
• Ask attendees to be your ambassadors!
Expect it to take time

• The number one way that people learn about Memory Cafes is word of mouth
  (Percolator survey, March 2019, n=67)

• Word of mouth takes time! (especially now)
Memory Cafés strive to be inclusive –

• Free of charge (donations accepted)
• Physically/digitally accessible
• Free of stigma
• Responsive to the different cultures and needs of the people whom you serve
Ask the Mr. Rogers question: Who are the people in your neighborhood, and are they coming to your café?
What does your “neighborhood” mean nowadays??

You decide.

• Some cafés still focus on serving their local geographic community through virtual platforms
• Some cafés in a region have joined to rotate virtual café gatherings
• Some cafés are advertising nationally or internationally
Steps taken

- Reach out to all communities within area, including faith communities, group homes for people with intellectual/developmental disabilities, and residences for older adults
- Build relationships with providers serving different communities
- Offer a range of music and food
- Represent many communities on flyer (images, language)
- Give guests from many cultural/linguistic backgrounds opportunities to tell their stories
- Include the experience of professional caregivers.
- Multilingual staff who are able to translate when needed
- Be Intentional!

- Percolator survey, December 2019, (n = 57)
Advantages to serving people at any stage of disease progression

• Café will not require screening or exclusion
• You will be able to serve people for longer, and build a sense of community (remember: disease progression can be rapid)
• Guests who have moved to LTC residences can continue to attend
Role of Café Coordinator and Volunteers
Facilitator/Coordinator

• Usually paid, often an employee of host organization
• Plans, schedules, and advertises the cafes
• Maintains a list of café attendees and their contact information; reaches out to people who stop attending
• Recruits, trains café volunteers
• Purchases supplies/food; manages technology
• Connects with other café leaders to share information

• Monthly cafés require about 20 hours per month
Volunteers are a plus – in person or virtual!
Get some tech volunteers!

• A great role for younger people

• Takes time but pays off: technology is key to accessing health care and other basic needs, as well as social connection
Activities that work for all
Principles

• Focus on process, not product
• Hold space for people living with dementia (care partners tend to jump in)
• “Dignified playfulness”
• Keep the plan simple and flexible; improvise based on responses
• One size does not fit all; get feedback from your guests
• For virtual cafes, facilitator needs to show MORE enthusiasm and energy. Engage people by name when possible.
Online cafés: activities

- **Conversation**: discussion of themes; timeslips.org “Beautiful Questions”
- **Games**: trivia, bingo/loteria, Headbanz (using chat box), Wheel of Fortune (using white board function)
- **Physical activity**: Zumba, Ageless Grace, BeSoul, dancing, yoga
- **Mindfulness/relaxation**: Self-Reiki, guided meditation
- **Slide presentation and discussion**: Tales & Travel literacy activities, bird talk, art education, nature photos
- **Singing, drumming**: (use household objects like spice jars)
- **Open mic poetry**
- **You can show each other special items in your homes!**
Virtual café tips

• See 6/10/20 Percolator meeting recording – guest artist panel
• Mute everyone for singalongs
• Be wary of showing videos on Zoom
• “Narrate” what’s happening for those on the phone
• Zoom: set to “Original Sound” if you are playing live music. Set to “Computer Audio” if you are playing recorded music.
Virtual café agenda

• 9:45: Guest facilitator signs on; Beth makes them a co-host. Guests begin to arrive.
• 10:00: Welcome everyone and start café.
• 10:05: Review Zoom controls. Ask participants to type their name in chat box.
• 10:10: Announcements – upcoming café, etc.
• 10:20 – 11:30: Guest facilitator leads interactive program.
• 11:30 – noon: Group discussion with student volunteers, using one of TimeSlips’ Beautiful Questions.
A little information about privacy

• We, the staff of JF&CS, will use Zoom privacy modes to keep this meeting as secure as possible.

• Your voice and/or picture will be shared with the group during the JF&CS Memory Café. You can turn off your video if you prefer.

• We will record today’s sing-a-long and share it with JF&CS café guests and others who might enjoy it.

• Please be aware that any people who are in the same room as a JF&CS Café guest could either overhear or see our gathering.

• We ask you to do your best to maintain the group’s privacy.

• Please choose a quiet, private spot in your house where you will participate.
Audio

Unmuted = we can hear you

Muted = we cannot hear you

• If you are joining us by phone AND by computer (both), please make sure you “leave computer audio”:
Using Chat

• Everyone: please type your name into the Chat box NOW. This will be our attendance list.

• Please use the Chat function anytime to communicate with Jane or Beth!
Resources
Archive of Percolator Quarterly Meetings

Percolator meetings are held quarterly in Waltham, Massachusetts and by Zoom/conference call. We began recording the meetings in June 2019.

- **June 2019 Meeting**: West County Memory Café of Shelburne Falls; supporting guests with Frontotemporal Degeneration (FTD) at a memory café
- **September 2019 Meeting**: South Shore Conservatory Memory Cafés; results of Percolator survey on how cafés respond to death and disease progression
- **December 2019 Meeting**: Burlington’s Memory Café; results of Percolator survey on how cafés create a sense of community and belonging
- **March 2020 Meeting**: Literacy-based Café programming; Brookline’s Memory Connections Café & Camp Memory Connections; Short brainstorm about the response to COVID-19
- **COVID-19 Response Meeting (3/24/20)**: How memory cafés are responding to the coronavirus. See the slides from the meeting.
- **COVID-19 Response Meeting (4/28/20)**: Idea exchange about virtual memory cafés. See the slides from the meeting.
- **June 2020 Meeting (6/10/20)**: Virtual JF&CS Memory Café; A panel of teaching artists spoke about their transition to facilitating virtual cafés. See the slides from the meeting.
- **September 2020 Meeting (9/10/20)**: Five memory cafés in the U.S. and Brazil adapt to COVID-19 through virtual or outdoor programming. See the slides from the meeting.
Wisconsin Best Practice Guides
https://wai.wisc.edu/best-practice-guides/
More Percolator Memory Café Network Resources

• Toolkit (English)  [www.jfcsboston.org/MemoryCafeToolkit](http://www.jfcsboston.org/MemoryCafeToolkit)
• Toolkit (Spanish) [www.jfcsboston.org/GuiaCafeDeMemoria](http://www.jfcsboston.org/GuiaCafeDeMemoria)

Videos include:
• Creating a Spanish-speaking Memory Café: [https://www.youtube.com/watch?v=Vn3-I0xjpFE](https://www.youtube.com/watch?v=Vn3-I0xjpFE)
• I/DD inclusive Memory Cafés: [https://www.youtube.com/watch?v=EE49z4CpyP8](https://www.youtube.com/watch?v=EE49z4CpyP8)
• How to create a Memory Café network: [https://www.youtube.com/watch?v=XSs0n4Hpt7U&feature=youtu.be](https://www.youtube.com/watch?v=XSs0n4Hpt7U&feature=youtu.be)
• TEDx talk: Memory cafes: making space for dementia and joy: [https://youtu.be/vje71rXP8Z0](https://youtu.be/vje71rXP8Z0)

And more!
More Memory Café Resources

National, regional or individual café sites:
• www.memorycafedirectory.com
• www.jfcsboston.org/MemoryCafeDirectory
• http://www.foxvalleymemoryproject.org/memory-cafes.php
• https://arthursresidentialcare.com/memorycafe/
• http://nymemorycenter.org/memory-arts-cafe/

Other café websites:
• www.memorycafecatalyst.org
• http://www.alzheimerscafe.com
• http://www.actonalz.org/engagement (see “meaningful engagement”)

Book: The Alzheimer’s and Memory Café: How to start and succeed with your own café, by Jytte Fogh Lokvig, available on Amazon
Where to find virtual memory cafés

National/global café listing:
www.memorycafedirectory.com/cafe-connect/

Submit your virtual café listing, and attend from anywhere!

Massachusetts cafes:
www.jfcsboston.org/MemoryCafeDirectory
Now being updated with virtual café information
Contact me!

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