Memory Cafés in Massachusetts

Percolator Memory Café Network Quarterly Meeting
June 10, 2020
Today’s Agenda

1. Housekeeping
2. A moment of acknowledgment
3. Announcements and Percolator updates
4. Presentation: JF&CS Memory Café – a transition to the virtual world
   Q&A, discussion
5. Teaching artists panel: Gary Glazner, Art Sullivan, Erica Curcio, Ismael Butera, Deborah Karpel, Monique Morimoto, Stephen Whitney
   Q&A, discussion
6. Next meeting: Thursday, September 10, 1:30 – 3:30 pm EST
Housekeeping

• This meeting is being recorded. The recording will be available at www.jfcsboston.org/Percolator in approximately 2 weeks.
• Please activate your video option if you have a web cam and would like us to see you!
• Please keep your audio muted unless you are speaking.
• Please use the chat function to send your questions and comments at any time.
Say hello! Please type your name and location in the chat box!
A moment to see and hear: systemic racism and dementia

- Risk of dementia
- Risk of late or incorrect diagnosis
- Lack of representation in research and organizational leadership
- Wealth disparities, making it hard to afford needed services
- Not enough culturally appropriate services
- What else do we need to see and hear?

- How do these dynamics play out in our communities? In our cafés?
Systemic racism and dementia: resources


- Risk of late or incorrect diagnosis: [Racial disparities in dementia misdiagnosis in US 2019](https://www.alz.org/research/)

- Lack of representation in research and organizational leadership: [Why African Americans often say no to clinical trials - PBS 2016](https://www.pbs.org/newshour/); [Efforts to diversify research NPR 2019](https://www.npr.org); [Vu Le’s Nonprofit AF – focus on diversity](https://www.npr.org);


- Need for culturally appropriate services: [University of Hawai’i at Manoa resource page](https://www.hawaii.edu/); [Diverse Elders Coalition](https://www.diverseelderscoalition.org)
Culturally appropriate Memory Cafés

All cafés should strive to be inclusive

• Ask the Mr. Rogers question – “who are the people in your neighborhood?”
• Key “levers” of inclusion include: outreach including relationship and coalition-building, imagery on flyers, choices of music, activities, language resources, etc.

Cafés are needed in multiple languages and all communities

• Covid-19 at least temporarily increased the cost of starting/sustaining a café
• Communities of color hardest hit by covid-19 are likely to struggle to start/sustain a café, due to competing priorities and lack of resources
• Funders take note!
Let us make this a time of hope

Seeing and hearing what has been unheard, reflecting and changing is a lifelong practice.

It is often uncomfortable. That’s okay.

Let us summon our courage to sustain our focus on how the US needs to change, and let us do our part to improve our country.
Comments and announcements
(keep them brief please!)
Percolator Updates
Memory Café directories

- National virtual café directory: https://www.memorycafedirectory.com/cafe-connect/

- Massachusetts café directory is being updated with virtual café status: www.jfcsboston.org/MemoryCafeDirectory
Percolator Resources

• **Percolator webpage:** [www.jfcsboston.org/Percolator](www.jfcsboston.org/Percolator)
  - Updated Memory Café Toolkit:
    [www.jfcsboston.org/MemoryCafeToolkit](www.jfcsboston.org/MemoryCafeToolkit) (English) and
    [www.jfcsboston.org/GuiaCafeDeMemoria](www.jfcsboston.org/GuiaCafeDeMemoria) (Spanish)
  - Meeting archives
  - Guest artist/activity facilitator directory
  - And more!

• **Percolator Google Group** (let Beth know if you didn’t receive an invitation)
Keep in touch!

- Sign up for Percolator mailing list at www.jfcsboston.org/Percolator

- If you are not receiving Percolator emails, check with me at bsoltzberg@jfcsboston.org. Your organizational server may be rejecting the messages.
JF&CS Memory Café’s Journey to the Virtual World
Many Memory Cafés going Virtual

Massachusetts Memory Cafés – June 2020 update

- Not meeting virtually (59.5%)
- In transition
- Currently meeting virtually (28.6%)
JF&CS Memory Café

- Started March 2014
- Partnership with student group at Brandeis University
- Meets one Friday morning per month, 10 a.m. to noon in Waltham, Massachusetts
- Began meeting virtually in April 2020
Steps in the transition: Platform

- Choose platform(s): Zoom and telephone
- Decide which security options to use
  - Pre-registration/unique Zoom link not required
  - Referrals go to me, then I send out Zoom information
- Prepare privacy information and send to guests
Dear JF&CS Memory Café Guest:

We are happy to host “virtual” JF&CS Memory Cafés! This message is to let you know that there are some special guidelines about privacy for these events. The virtual JF&CS Memory Cafés will be held over video conferencing. If you decide to participate, you are agreeing to the following:

- Your voice and/or picture will be shared with the group during the JF&CS Memory Café.
- We will record the activity that is facilitated by our guest artist, and we will share this recording with JF&CS Memory Café guests. We may share this recording with other individuals who could enjoy it, and with community service providers also. We will not share any recordings that include the video images of our café guests, unless we ask your permission first.
- We, the staff of JF&CS, will enable all available encryption and privacy modes when we are using teleconferencing.
- Please be aware that any people who are in the same room as a JF&CS Café guest could either overhear the guest’s communications or have access to the technology that the guest is using. This may include family, friends, employers, co-workers and others.
- We ask you to do your best to maintain the group’s privacy.
- Please choose a quiet, private spot in your home where you will participate.

Please contact Beth at bsoltzberg@jfcsboston.org or 781-693-5628 if you have any questions or concerns. Thank you!
Steps in the transition: Guests

- Determine whether most guests would be able to use Zoom, telephone, etc.
- Plan to mail necessary materials in advance to guests who only use phone (only possible for known guests)
- Develop fillable registration form for new guests
- Establish a process for new referrals: RSVP to Beth, then Beth will send out registration form and Zoom/call-in information
- Note that it is risky to share a Zoom link on social media or large mailing lists
Steps in the transition: Guests, continued

• “How to join a Zoom meeting” video sent out to guests with the regular monthly email mailing

• Tech volunteers now available
Steps in the transition: Activities

Activities

- Talk with guest facilitators to determine comfort with facilitating a program virtually, and confirm a fee
- Choose activities that would work by telephone, too
- Mute everyone when singing (most of the time)
- Sound quality can be improved greatly by professional microphone and other sound equipment
April, May, June JF&CS Memory Café activities

Songs of Spirit and Resilience, sing-along

The art of Marc Chagall, art education; not recorded

Sentimental journey; guitar and singing with slides, sing-along

Recording to be posted in about a week
Facilitation

- I don’t use the waiting room; I sign on 15 minutes early and let people start to arrive
- Review Zoom controls with guests at the beginning
- Ask everyone to type their name in chat box (helpful for attendance because screen names are not always sufficient); encourage chat messages throughout
- Try to welcome and engage with guests by name
- Periodically unmute everyone for discussion/read chats aloud
- Pin or spotlight speaker’s video when recording video
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.
Quick review of Zoom controls

• Can you HEAR and SEE us?

• Can we HEAR and SEE you?
Video

Click Here To Start or Stop Your Video
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!
Moving the little videos out of the way

• Doug will show slides while we sing
• You can move the little videos out of the way with your cursor, or choose “side by side” in view options
Outreach & attendance

- Overall, attendance is about the same as before
- Some “regulars” opted out of the virtual café
- Several new guests have joined
  - Continue monthly email to providers’ list
  - Listed on https://www.memorycafedirectory.com/cafe-connect/
- One new family has joined from Georgia; others have been referred within Massachusetts but some are from farther away than is typical
Staying connected

• Round of phone calls
• Offered student volunteers to be phone friends
• Handmade cards made by volunteers sent out with monthly mailing
• Now offering tech assistance by volunteers
Feedback from guests

- Strong sense of community and connection during the virtual café
- Many guests stay for the full two hours
- Several take part who could not attend in person (e.g., a couple at home on hospice care)
- Several guests with advanced dementia stay engaged and enjoy it
- The recorded portions have been appreciated by some who find it hard to attend synchronously or want to revisit the experience
What it’s like to run the virtual cafe

- Less expensive to run (no food, paper goods, other materials)
- Haven’t tried yet to get sponsors for virtual café sessions
- A little more planning time (slide preparation)
- Much less set-up and break-down time
- Once new systems are established, the virtual café will probably take 2 hours fewer per month to run
To be decided

When we transition back, will we keep a Zoom option?
Discussion
Teaching Artists
Journey to the Virtual World
Teaching Artists share their transition to the Virtual World
Joining Us Today

- Gary Glazner, Founder and Executive Director, Alzheimer’s Poetry Project
- Art Sullivan, Dance Instructor, Parkinson’s Dance
- Erica Curcio, Registered Art Therapist and Licensed Mental Health Counselor
- Monique Morimoto and Stephen Whitney, Drumming instructors, SoulWorks Rhythm
Gary Glazner
Founder and Executive Director, Alzheimer’s Poetry Project, and host of Memory Arts Café, Brooklyn
Hope is a Thing with Feathers

https://www.youtube.com/watch?v=QtsxpEZcDLA
Past Experience in the Virtual World

• Teaching: Alzheimer’s Poetry Project trainings using virtual platforms
• Performance: 1997 Poetry Slam in an AOL Chatroom

Platforms used: Zoom, Facebook Live, Telephone
What’s New

Now doing ALL workshops virtually
Planning in the Virtual World

• Hold a tech rehearsal if possible

• Care partners handle most tech aspects of taking part in Poetry Parties or Memory Arts Cafes; they need to know how to use the platform
Facilitation in the Virtual World

• “Call and response” involves a delay on Zoom; I tell the participants to expect chaos and that it will be fun anyway

• We alternate between group performance and one-on-one work with participants

• While I work with one person, the rest of the group may say the words at home

• We also play songs and have participants sing along

• Periodic conversation helps to increase engagement
Facilitating on the Telephone

**Poetry Party** is a 30 minute to hour long show that sounds like an old-fashioned radio show. Suitable for all ages! Funny poems! Happy poems! Poems that make you want to Dance. Love poems! Silly poems! Won’t you listen in and take a chance?
Pearls of Wisdom

• Validation techniques are always important - even more so when using online platforms.

• A key technique is repeating and rephrasing a person’s words to let them know you have heard what they are saying

• In our trainings for use of online platforms we emphasis this as a skill that we can improve, using validation.
Fees

- Tend to be lower for virtual programs
Unexpected Gifts

This morning our session included a woman who described sipping rum as a young person growing up in the tropics. She sang a song about drinking rum in Spanish and had us all dancing to the song.
Contact information

Gary Glazner

- Founder and Executive Director, Alzheimer’s Poetry Project
- Visit www.alzpoetry.com
- Contact: garyglaznerpoet@gmail.com
Art Sullivan
Dance Instructor, Parkinson’s Dance
New to the Virtual World

• Platform used: Zoom
• All programs are currently being provided live
• In the process of recording Zoom sessions
Planning in the Virtual World

- Camera set up – is room and instructor visible head-to-toe? (Purchase of a special camera was required)
- Room set up – is the space adequate? Are there tripping hazards? How is the lighting?
- Sound check – test microphones to be sure of quality of sound. (Purchase of a USB microphone was required)
Facilitation in the Virtual World

- Continuous check in throughout the class
  - Can students hear me?
  - Can they hear the music?
- Quality of sound and voice?
- Problems?
- Suggestions?
Pearls of Wisdom

• Even for a recurring class, send a Zoom invitation for each class meeting, including the full Zoom invitation with URL and password if necessary.
• Have your phone ready and nearby because someone will be calling with access problems.
• Mention students’ name frequently.
• Speak directly to individual(s) one at a time. If necessary, mute all others except one to whom you are speaking.
• Choose familiar music; engage their childhood memories with songs appropriate to their youth and teen years.
Fees

• Same fee as for in-person programs
What is hardest

Learning the technology: an ongoing and time-consuming process
Unexpected Gifts

We will never have to cancel a class in the future because of the weather!
Contact information

Art Sullivan, Dance Instructor
• Contact: Arthur.Sullivan@yahoo.com
  or asullivan@jfcsboston.org
Erica Curcio
Registered Art Therapist and Licensed Mental Health Counselor
New to the Virtual World

• Platforms used: Zoom and Instagram (handle: instagram.com/thetravelingarttherapist)
• Looking into additional platforms
• Interactive groups
Reinventing in the Virtual World –
Caregiver Companion Art Therapy Kits

• Mailed to participants or centers can have pickups

• All the supplies needed for an individual art therapy session, or a group program.

• Memory cafés could host a group program, with enough advance planning to allow for purchase and mailing of kits.
Planning in the Virtual World

• Consider programing that could extend beyond the memory café. Could you provide the care partners with a new artistic skill that they can use again?

• Develop a program that requires minimal supplies, and uses things a person might already have at home – tissue paper, scissors, office paper, etc.

• Also consider natural items that the person living with dementia could find on a walk. This could be a form of engagement even before the group occurs.

• Create a suggested supply list with words and images.
Planning in the Virtual World

• Consider sending a template for participants to print out. This requires a printer. However, if it’s simple, participants might be able to draw the template onto a sheet of paper.

• Check in with the moderator and arrive earlier than participants
Facilitation in the Virtual World

• Start by describing what will happen during the memory café. Show a demo of what will be created.

• Go through the supply list with participants and give them time to go get supplies if they find that they don’t have them.

• Prepare a conversation-starter so that you can lead a discussion while some participants are looking for their supplies.

• It’s really important to connect people. Allow everyone to introduce themselves. Suggestion: leave everyone unmuted and remind them to let others finish speaking before they start to speak.
Pearls of Wisdom

• Design a program in which participants cannot fail.

• Allow for a participant to look through a magazine if they can’t figure out the program.

• Enable a participant to explore the supplies without having to do the activity. With this in mind, aim for tactile materials when setting up your supply list. Art can be really difficult for someone living with advanced dementia.
Fees

- Fees will vary based on whether supplies are purchased from me or the participant is providing their own supplies.
- Groups start at $100 for 1 hour without supplies.
- Individual services are $125 for 1 hour.
What is hardest

• The loss of the hands-on experience.

• As an expressive therapist, I am aware that participants aren’t always given the freedom to fully express themselves because I’m not there in person. It becomes somewhat instructional.
Unexpected Gifts

- The joy of reconnection.
- Enabling someone who is extremely isolated to see and speak with others on Zoom and to create together.
- The wonderful encouragement participants give one another and the possibility that a loved one can try this program again with their care partner because now they have the necessary supplies.
Contact information

Erica Curcio, Registered Art Therapist and Licensed Mental Health Counselor

- Visit: [www.ericacurcio.com](http://www.ericacurcio.com)
- [instagram.com/thetravelingarttherapist](https://instagram.com/thetravelingarttherapist)
- Contact: [Erica.curcio@gmail.com](mailto:Erica.curcio@gmail.com)
Ismail Butera
Musician,
https://www.facebook.com/ismail.butera

Deborah Karpel
Musician,
www.deborahkarpel.com
Musician in Residence, Memory Arts Café, Brooklyn
New to the Virtual World

• Platform used for live programs: Zoom
• Ismael also uses Zoom for recorded programs
Planning in the Virtual World

- I set up a Zoom session, then ask the host to share the information with the participants.

- It’s important that the host shares this information in a timely way so that as many people can participate as possible.

- Allow time to adjust video and sound quality.
Facilitation in the Virtual World

I try to keep the experience as close to a live session as possible. This means keeping participants unmuted so I can hear them singing along and so that they can converse.
Facilitation in the Virtual World

I’ve discovered that the less facilitation I do with this group the better. It’s cacophonous at times but people remain engaged. Waiting rooms, mutng, things like that only open up avenues for disconnection and confusion.

I like to single people out separately and direct some attention specifically from time to time in the program.
Pearls of Wisdom

It's important to call participants by their name, and engage with them on a one-to-one basis as well as a group.

Encourage a live session feel as best as one can.
Fees

• Generally the same as before

• Flexible
Unexpected Gifts

Deborah:
• So far, I’ve been getting smaller groups (those who have a care partner who can manage the tech.) This makes the groups more intimate.
• I also like seeing them in their homes. There is a sense we are really in each other’s lives.
• Even though I am a music performer, I like to mix in drawings I’ve made, signs and items in my home. It just is another way to connect and share something of myself.

Ismael:
• Having other artists and care workers join in makes for a positive session.
Contact information

Ismael Butera, Musician
• Visit: [https://www.facebook.com/ismail.butera](https://www.facebook.com/ismail.butera)
• Contact: accorditunes@yahoo.com

Deborah Karpel, Musician
• Visit: [www.deborahkarpel.com](http://www.deborahkarpel.com)
• Contact: debkarpel@gmail.com
Monique Morimoto and Stephen Whitney
Founders of SoulWorks Rhythm®
www.soulworksrhythm.com
New to the Virtual World

- Platform used: Zoom for live programs
- Looking into Qiqochat -- https://qiqochat.com/about
Recorded programs

We record instructional pieces on Android, post to YouTube and share the link via our Facebook page and via email to activities directors and other clients.
Recorded programs

Virtual Community Class: Music with Monique and Steven

With Alzheimer’s Foundation of America
Planning in the Virtual World

For a live or recorded program that invites participation:

• A week in advance, ask the host to send our Found Sound demo video to participants, and ask them to bring something to make sound with.

• Ask the host for a general sense of participants’ familiarity with Zoom so we can be prepared to go over the basics.

• We set up in the same place in our house and have a standard background, opening and closing. The phone is on a mini-tripod about 3 feet away. We improve lighting with an overhead light.

• We enable original sound on our Zoom meetings. It would help if participants could do this, too, but this might be difficult for those who are less comfortable with technology.
Room Set-up: Then and Now
Facilitating in the Virtual World

- One of us manages Zoom. This person sets up their instruments close to the computer to manage muting, unmuting and in order to “lean in” to the participants and engage.

- It can be difficult to hear participants through Zoom, so it is often necessary to encourage them to speak up or move closer.
Facilitating in the Virtual World

• We attempt to encourage everyone’s unique self-expression.

• We exaggerate the physical movements to provide visual cues to participants.

• We must slow down, repeat instructions and build in ways to help create a sense of community and connection.

• We play shorter sequences of 3 minutes because of attention span and the challenges of participants not being able to hear each other well.
Pearls of Wisdom

- Consciously focus on being in relationship to the person, not the picture on the screen. This helps build and maintain connection through the ethers.

- In virtual programs we don’t have the energy of the room to enliven us. So we work hard to get our energy up, be animated, engage and shining through the technology to make connections.

- Working through being camera shy can also take time, especially if you are sending recordings out. Doing this in the spirit of service and creativity helps. It will not be perfect and that is OK!

- We expect that it may be hard for participants to “get” an activity that may be brand new (drumming), so we appreciate any and all participation! The participation of care partners can help encourage engagement.
Pearls, continued

- Bring your whole beautiful selves to this.
- Set an intention for the session – who do you want to be for your participants? What do you want them to leave with? Teach to that.
- Be willing to fail, be patient with technology.
- Value your offering.
**Fees**

**Live programs:**

- What costs us less: we don’t have to lug 20+ drums and percussion instruments in and out of the house to the car and in and out of the facility.

- What costs us more: virtual facilitation takes more emotional energy.

We are charging less for our Zoom programs even though we are working harder to facilitate them. Monetizing in the midst of so many free offerings has been a challenge.

**Recorded programs:**

We have provided recordings for the Alzheimer’s Foundation of America and other uses for free. We retain full rights and ownership of our raw videos, the final posted versions, and the links to the FB page. We appreciate the exposure and feel it is important to give back right now and to keep in touch with our clients and create new opportunities. We appreciate references to our FB page and website.
Food for thought

Please expect to pay teaching artists and facilitators.

Perhaps setting an across-the-board rate for a live virtual program would be useful. We can work within that structure.

I don’t expect that we will be doing anymore live rhythm events for seniors any time soon. This is the new normal.
What is hardest

We miss the dynamism, spontaneity, interaction, sound and vibration of being in a room drumming together and the sense of community and oneness this creates.

We miss seeing the immediate effect this has on participants.

The technology is limited in terms of sound quality.
Unexpected Gifts

• This has caused us to get out of our comfort zones and be creative!
• Participation from across the country in a live session creates a sense of oneness, wider reach, connectivity.
• People have expressed gratitude for the opportunity to participate.
• And 763 views so far on the Alzheimer’s Foundation site!
Contact information

- Monique Morimoto and Stephen Whitney, Founders of SoulWorks Rhythm®
- Visit: www.soulworksrhythm.com
- Contact: mgm@soulworksrhythm.com or 617-512-8160
Discussion
Save the date for the next Percolator Quarterly meeting:

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June 10, 2020