

# Dementia Minute – Vital Cafés Adapt to Going Virtual

September 3, 2020



It's a chance to "just be." That's how the Dutch founder of the Alzheimer's café concept, Dr. Bere Miesen, described his intent in 1997, and it remains its chief benefit decades later, after spreading worldwide. Beyond that, many differences remain. Dr. Miesen was adamant in calling his gathering places Alzheimer's cafés because he was trying to confront – and remove – the stigma attached to the disease. Today, some people have broadened the name to "dementia cafés" to indicate their willingness to embrace people with any form of dementia, but the most common name is "memory café," even though it's a misnomer. People living with dementia have many more symptoms beyond memory loss, and "memory café" sounds like it's for boosting one's memory. Still, some cafés hide their identity even further. Gail Sonnesso, Founder & Executive Director of GEM (Gentle Expert Memorycare) Adult Day Services, Inc. on North Carolina's Outer Banks, calls her iteration Harmony Café, noting that many attendees still feel the stigma of the disease too strongly to be more direct. Plus, because music is a big part of every gathering (thanks to her musician husband), harmony is a fitting choice.

One way in which the cafés are alike is that they are not respite or day care programs. Many meet only once a month, or at most once a week for a one- to two-hour session. A care partner (spouse, adult child, sibling, friend) is always expected to attend with the person living with dementia. Their presence serves multiple purposes. Care partners have a chance to interact with others in the same role – people who understand them. They also have the chance for casual, normal, social interactions which are vital to wellbeing. Equally important, they are exposed to the modeling of effective communication with people living with dementia, the lack of which causes much of the tension that can develop between the partners.

Ms. Sonnesso, who has an MS in Rehab Studies, along with an extensive background in dementia care, both in education and career positions, notes, "I have a higher expectation of what [the person living with dementia] is capable of than most." While care partners are used to "doing for," she gives them a chance to lead. Seated exercise is a part of every session, and it is a person with dementia who leads the swim strokes or arm punches, for example. Other aspects of every session in which they might take a leadership role include a sing-along (and dancing), an art project (many are good at helping others) and a specialized bingo game that features Outer Banks landmarks.



During the pandemic, Harmony Café has gone online, but the programming has remained much the same. Song lyrics, exercise routines, the specialized bingo cards, and patterns for art projects can all be emailed. Sometimes, if additional art supplies are needed, Ms. Sonnesso has met up with families in parking lots to give out a bag of the required materials. As for bingo prizes, those have to come from the families, and may include simply eating the M&Ms they have used for markers.

But programming is another way in which the cafés differ. Some, in particular those that gather in a real restaurant or coffee shop, meet for conversation and light refreshments with no planned agenda. It's the "normal outing" that is the biggest attraction. Now that many cafés have begun meeting online,

# Dementia Minute – Vital Cafés Adapt to Going Virtual

---

September 3, 2020

conversation and catching up with everyone is often all that's required. They may miss the in-person hugs, but they are delighted to see familiar faces.

That has been the experience of Jytte Lokvig's now online Alzheimer's Café in Santa Fe. Pre-COVID, they met monthly for years in a lounge-like classroom at the local children's museum, what Ms. Lokvig describes as a "bright, colorful, cheerful place." Although she has a PhD in Management of Alzheimer's Care, she has a background in Montessori and believes strongly in letting people pursue what they are already interested in. She always came prepared with two or three possible projects to work on, plus song books, joke books and other materials, but let each gathering flow at its own pace. In terms of art projects, she is especially fond of collages, partly because "there is no wrong way to do it," partly because it reveals the interests and world view of the person making it, and partly because she has an enormous collection of beautiful art and scenic magazines donated by friends. Now wide-ranging conversation is the main appeal.

In 2008, Dr. Lokvig established the first Alzheimer's Café in the U.S. and has since helped many others get started in the western hemisphere. As a strong advocate of Dr. Meisen's ideas, she notes, "If it's called an Alzheimer's Café, I likely had a hand in it." But much as she would like to overcome the hesitancy of so many to try to confront and dissipate the stigma of dementia, she is most of all an advocate for the cafés themselves.

Both Jytte Lokvig and Gail Sonnesso recognize the need is enormous, and both are eager to talk with others wanting to know more about starting their own – or who simply have questions about dementia. You can learn more about Ms. Sonnesso's work at [www.gemdayservices.org](http://www.gemdayservices.org) or contact her directly at [gsonnesso@gmail.com](mailto:gsonnesso@gmail.com). Reach out to Dr. Lokvig at [lokvig@gmail.com](mailto:lokvig@gmail.com) and check out her books on Amazon. You can also download [this](#) guide to starting your own café which served as the handout to a session given in part by Dr. Lokvig at a Dementia Action Alliance conference.

*Kathy Laenhue is chair of Dementia Action Alliance's Arts Work Group made up of artists living with dementia and those who work in the field of dementia and the arts. Both Gail Sonnesso and Jytte Lokvig are valued members of the work group. Learn more at [www.DAANow.org](http://www.DAANow.org) or contact Kathy at [Kathy@WiserNow.com](mailto:Kathy@WiserNow.com).*



Published by [Kathy Laenhue](#)

Creative brain power is our main game

Published • 3d [70 articles](#)

This week's Dementia Minute is about Memory Cafes for people living with dementia. During COVID they've gone virtual, but are still vital. [hashtag#dementia](#) [hashtag#caregiving](#) [hashtag#memorycare](#) [hashtag#dementiacare](#) [hashtag#socialdistancing](#) [hashtag#virtualcare](#) [hashtag#virtualsolutions](#)

---