An Alzheimer's Café in Every Community: The Simplest, and Yet Most Effective Project You'll Ever Embark Upon

Jytte Lokvig, Ph.D., Founder of the Alzheimer's Café, American Model Author of Alzheimer's A to Z and The Alzheimer's Creativity Project.

Jan Olsen, Gerontologist. Animo Geriatric Consultation. Santa Fe, NM

Cecily Kaplan, Senior Programs Director for the Phinney Neighborhood Assoc., Seattle, WA

Jytte Lokvig opened the first Alzheimer's Cafe in North America in 2008. The concept has since been spreading to 85 Alzheimer's Cafes and similar programs known as Memory Cafes. This international movement represents an important shift in our approach to dementia and other brain diseases.

The Alzheimer's Cafe is a monthly or biweekly celebration of the person with dementia as well as family, friends and caregivers. It focuses on the person beyond the disease and works to diminish the stigma. We guide participants through the process of opening a cafe.

Keystones of the Alzheimer’s Café are

LOVE AND ACCEPTANCE

Jytte Lokvig, Ph.D. - lokvig@yahoo.com - 505.466.8195 or 505.501.2412 (c.)

Jan Olsen - janolsen@cnsp.com - 505.424.0577 or 505.699.2643 (c.)

Cecily Kaplan - cecily@phinneycenter.org -206.297.0875 or 206.351.1460 (c.)
The Alzheimer’s Café
And its cousins, Memory Cafe, Dementia Cafe, Nostalgia Cafe, etc.

Why?: In our culture we segregate our old people; we take them out of circulation in the name of "caring for them." We move them into care facilities, away from the rest of the population.

• The loneliness and isolation is often worse for people who live at home with family or a caregiver. Generally their only contacts with the outside world are trips out of necessity, most often related to their disease, i.e. to doctors’ offices.

To the rescue: The Alzheimer's Café. A very simple idea: a monthly gathering for individuals with memory loss with their caregivers, and/or friends and family in a safe, supportive, and engaging environment. It’s a time and place where everyone can interact, laugh, cry, find support, establish friendships, and share concerns without feeling embarrassed or misunderstood. It gives people with the disease time to share a positive experience with their caregivers.

The movement quickly spread all over Europe and in 2008 Dr. Lokvig started the first Alzheimer’s Café in the US. Her Santa Fe, NM café remained the only one in the northern hemisphere until a short notice in the AARP Bulletin in April of 2011 brought the concept to the attention of the greater eldercare community. Dr. Lokvig advised many other communities in getting their own cafés started.

As of July 2013 we have more than 85 Alzheimer’s Cafés and Memory cafés in the US. Although these cafés are all a little different from each other, they tend to fall into one of the two general categories: The European model as initiated in the Netherlands in 1997 and the American model, conceived by Jytte Lokvig in 2008.

"The American Model" was established by Dr. Jytte Lokvig in 2008 with her Alzheimer’s Café in Santa Fe, NM. The American Model focuses first and foremost on the person. It’s a celebration and a respite from the disease. Participants explore art, music, poetry and socialization ... and laugh a lot!

"The European Model" feature presentations and information on Alzheimer's issues combined with a social hour. Caregivers are offered consultation and support.

For more information: http://www.alzheimercafe.co.uk/
(or if you read Dutch: www.alzheimer-nederland.nl/)

The Alzheimer’s Café is the brainchild of Dutch psychiatrist Bére Miesen, who explains:

“ The Alzheimer’s Café is an informal way to make contact with each other, to receive a consultation and feel at home. In the Netherlands, patients feel they have a place to just be. This way the patients and their families don’t have to deny or avoid the illness.”

The very first meeting of the café in the Netherlands on Sept 15, 1997 drew just under 30, but attendance quickly doubled and tripled.
Starting Your Own Café

Simple needs:

Venue:
1. A venue with a warm and inviting atmosphere, not too big and not too small. (If possible at no charge.)
2. Comfortable furniture. (We like a single oversized table with enough chairs for all our guests—up to 20.)
3. Easy access
4. Plentiful parking
5. Wheelchair accessibility and handicap parking
6. Preferably a venue not related to anything having to do with elders or the medical community. (Several group meet in commercial cafés. Others meet in theaters and two in Children’s museums.)

Details:
1. A host or hosts with experience with Alzheimer’s and dementia
2. Decide which model you want to follow: The European or the American
3. Leaders committed to an ongoing project (consistency and continuity are important)
4. A modest spread of snacks, fruit, and drinks
5. Fun activities: music, arts and crafts projects (see addendum)
6. Guests (Speakers if you’re following the European Model)
7. A set time and place
8. Open invitation to the community at large
9. Establish relationships with local media

What we’ve learned:
1. Let go of expectations. You never know who’ll show up.
2. No solicitations! Our philosophy for the American Model: We think of our cafe as a private party at our own house. It’s first and foremost a celebration. That does not preclude spontaneous conversations of any sort, including “serious” topics. The European Model combines a social time with presentations and discussions on relevant topics.

We’d be more than delighted to help you through this process. Feel free to contact us.

Jytte Lokvig  505-466-8195 or  lokvig@yahoo.com
Jan Olsen  505-424-0577 or  janolsen@cnsp.com

For the US national registry of Alzheimer’s and Memory Cafés, go to:  www.alzheimerscafe.com

When you open your doors, we want to add you to the registry. Contact us at  lokvig@yahoo.com
Asheville, NC: I felt the need for the Memory Cafes because I run support groups for people who have a diagnosis and it was clear that they were all hungry for social activities for more interaction together in between our support group sessions. It also became clear that the couples (caregiver and person with diagnosis) needed to have something they could both enjoy.

The Alzheimer’s Café

First and foremost: Make sure that all your volunteers understand the basics of communicating and interacting with people with Alzheimer’s:

**Communication**

- Avoid Babyspeak - use normal adult speech
- Avoid: The word “No”
- Avoid: “Do you remember?”
- Use with care: “Do you want?”
- Never argue, scold, correct or criticize
- Respect altered realities
- Use Diversions and Loving Lies
- Compliments go a long way
- Use humor

**Fun Activities**

(Much more in *The Alzheimer’s Creativity Project* by Jytte Fogh Lokvig, Ph.D.)

**Celebrations:**

Anniversaries of your cafe, of course
- January 3  *Fruitcake Toss Day*
- January 21 *National Hugging Day*
- February 7 *Wave All you Fingers at Your Neighbor Day*
- February 11 *Make a Friend Day*
- February 24 *National Tortilla Chip Day*
- February 26 *Tell a Fairy Tale Day*
- March 10 *Middle Name Pride Day*
- March 14 *Learn about Butterflies Day*

Make up your own celebrations!
Music, Dancing, and Singing

Music is an important component of the Alzheimer’s Cafe, both as pure entertainment and as a shared experience.

Originally we had scheduled professional musicians to entertain at our café for the next several months, but a group of our guests requested that we stop that because the music was too noisy for them to hear each other and they wanted to talk and get to know each other. I cancelled the musicians and for the next couple of years we used our songbooks and a cappella.

Our selections include *You Are My Sunshine*, *How Much Is That Doggie In The Window* and several John Denver tunes.

We’re getting very good at John Denver and what we call *Creative Harmony!*
Making Stuff

The Café is for the pleasure of our guests and it's important for them to have choices of what to do, so we always keep supplies on hand for different projects, i.e. collage making, painting, jewelry making and even poetry writing.
GAMES AND GOOD LAUGHS

The essence of an Alzheimer’s Cafe is bringing everyone together in an accepting and non-judgmental environment. Caregivers and their charges have the opportunity to make friends independently of each other.

Our cafe has acted as the catalyst in many friendships that started at the cafe and have continued beyond our monthly meetings. Some of our regulars in Santa Fe formed a walking club and an art club.

Just in case, we keep a ring binder full of FUNNIES: Stupid Laws, Disorder in the Courts, quotes from Groucho Marx, George Burns, and ZsaZsa Gabor in addition to one-liners, hilarious classified ads.

From ZsaZsa:
“I’m a marvelous housekeeper. Every time I leave a man, I keep his house!”
Comments from our guests in Santa Fe

Thank you so much for all your work in putting on the Alzheimer's Cafe. I believe that it was God's plan with the way we heard about it. During the course of my husband's disease things have just come to us when we needed it most. That day [the café] has meant so much to me and my husband. I saw a part of him that I had not seen in a very long time. He was smiling, confident, uninhibited. These things have all been partially missing for the past seven years. Thank you for your work and commitment to others with dementia.
Deb Dalton, Los Alamos [reprinted with permission]

Thank you Jytte,
Jim and I will be there in March. Your guidance and support are such a Blessing to us. Thank you. Thank you, Thank you, Deb and Jim Dalton

Alzheimer's Cafe has helped me greatly. As a 42-year old caregiver, I work with people with dementia and am always looking to bring them to the café; there's always something interesting and stimulating for us to do. The Alzheimer's Cafe offers a unique enrichment to the life of the person living with Alzheimer's. Thank You, Scott McKinnon

I think the nicest thing about the Alz. Cafe is that it's different each time. It's always great to see the regulars and to get to know them better, but new people are always showing up. Jytte, you are such a joy and your spirit infuses each visit with love and playfulness! Love, Doris Sarhanis

"Thank you for reaching out to the people who are starting their long 'lonesome road'." Ellie Roy, Café volunteer, lost her husband to Alzheimer's.

"It's more relaxed, it's easygoing, and it's fun. We're seeing incredible support from strangers. You've go several people who have no connection to you and they're saying, 'Hey come here, let's talk'." ~Café attendee

The Alzheimer’s Café’s business is - - - laughter, camaraderie, understanding, relaxation, information, art and music in the midst of the often bleak clinical world of “living with dementia.” The café is open to those diagnosed with memory loss and those family members, friends, and professionals who care for persons with memory loss. ~Café attendee

I’m a gerontologist. I have met and worked with many families affected by memory loss. I’m acutely aware of the daily grind of isolation, doctors’ appointments, little social contact, medicines, fear, shame, burn-out, frustration and extreme fatigue for both caregivers and the ones cared for. ~Café attendee

If you were to visit the Alzheimer’s Café, my guess is you would not know whose memory has been lost. You would just see a group of folks having fun, relaxing and enjoying being together.
June 2013 Survey
We recently sent out a survey to several existing Alzheimer’s and Memory Cafés - so far we’ve received 11 responses. These are the findings:

FINANCIAL ARRANGEMENTS:
All cafes responding are not-for-profit. None pay rent. All except one use volunteer staff. The exception has a grant supported salary for the administrator. Most receive support for snacks from the venue or a supporting agency. Some solicit donations to cover the cost of snacks and supplies for activities. So it is safe to say that an Alzheimer’s café can indeed exist without a huge funding source.

LOCATIONS:
Some cafes are located in churches, some at senior centers or senior housing. Two, such as ours in Santa Fe, NM, are located at Children’s Museums. Two more are located in actual cafes and others at senior service sites. So you can see there are multiple options.

FORMATS:
All the responding cafes are using the social American model format and all continue to like the way it works for their communities and guests.

None screen their guests and none report problems as a result.

All have professionals or trained volunteers in attendance who are able to diffuse any problematic behaviors.

Most cafes were initiated by one person’s enthusiasm for the original concept as presented in Holland, as a place for persons with AD to feel acceptance, normalcy and to enjoy a respite from medical scrutiny.

LETTING THE COMMUNITY KNOW ABOUT THE CAFÉ:
Most use word of mouth, senior service announcements, newspapers, websites, and support group announcements. There are many avenues to get the word out.

CHALLENGES:
Reported challenges include keeping carepartners and caregivers interested and low attendance at times.

For the national registry of both Alzheimer’s and memory cafés:

Go to: www.alzheimerscafe.com
We asked folks to elaborate if they so wished. Here are some of their responses:

• What has worked particularly well for you?
  
  **Asheville, NC:** The casual drop-in nature of the Cafes makes it easy for people to test them out, stay as long as they want. We have been fortunate to have many couples attend several of the cafes, giving them 4 locations over the course of a month for a social activity together. Live music at various Cafes has been a big hit - we have had dulcimer, hammer dulcimer, guitar, piano, sing-alongs –

  **Brooklyn, NY:** We have a guest artist at each event. Gary Glazner, founder of the Alzheimer’s Poetry Project, hosts the events and interviews the guest artists. The participants meet the guest artist during the socializing and ask questions during the interview. Each guest artist then leads the group in the creation of a new work of art. We have created dances, songs, poems and visual artwork. For our one year anniversary we partnered with the Brooklyn Museum and held an event with over 100 people attending. We have also had success in doing off site events at the Aquarium at Coney Island.

  **Lebanon, NH:** Everyone LOVES LOVES LOVES having student volunteers! My sorority sisters from Dartmouth College come every month, usually 10-15 at a time. This has been an enormously successful part of our Cafe - both sides enjoy interacting with each other, and it enhances the socialization portions of our program. I could go on and on, and feel free to ask questions, but I'll leave it there for now.

• Any good changes you’ve made.
  
  **Lebanon, NH:** We didn't start with student volunteers; that came after 3 months of the program and realizing that we could use some more help. We also moved to a new location in May 2012 (after starting in Jan. 2011) because we out-grew our old space. We now often have nearly 70 attendees (40+ guests, entertainment groups, and volunteers)

  **Minneapolis, MN:** Meeting twice month 1-3 after lunch and before dinner, yet many come and buy lunch and eat during our meeting as well while others eat snacks.

  **Murfreesboro, TN:** We had a musician/ singer with his guitar- retired guy who knew wonderful songs and some of us sang along. We had been wanting to have music sometimes in addition to our conversation and mental games.

  **Erie, NY:** The agenda – a mix of activities including memory games, crafts, exercise, old trivia that we do together, Tai Chi, music, Bingo (we cheat so the care receivers & caregivers win, not the volunteers), bean bag toss, have a golf tee, “What’s in the Sock? Game,” etc. We don’t do the same things every month. Everyone loves the “Prize Basket” – filled with small donated items, some from health fairs, etc. - Bingo winners often select a “kids” item to take home to a grandchild. Being flexible and sensitive to the needs of the people attending. Some (care receivers) men just want to sit and talk, we have a retired judge and a professor who don’t enjoy
physical activities, but get into word games (with a volunteer discreetly joining in) and visiting with each other. Other men love the bean bag toss and get a rousing game going, including cheerleaders (usually the volunteers). Encouraging the women caregivers to do things with each other - they really appreciate the crafts - and we’ve seen them exchanging recipes and helpful tips.

Richardson, TX: Our simple icebreaker: introductions at the start of each meeting, has worked well to get our meetings started. A simple guided project (making Valentine’s Day cards with rubber stamps & glitter glue was enjoyed by all). Members bringing their artwork, woodworking projects or other hobby items is also fun to share.

Sacramento, CA: My group loves games, so I invent silly games that test eye-hand. Latest was one I saw at park called "washers". You toss a washer toward the holes on board marked 5, 4, 3 you have to get 10 pts. to win. Also they loved pin the green toupee on the paddy raccoon so he can go celebrate St Paddy's (pin tale on donkey). Getting my group to perform, take pictures, make stuff for me (one caregiver made a great donation jar) AND thereby OWN their own CAFE.

Asheville, NC: We involved the leaders of the three church cafes in Asheville on the planning team for the conference, "The Sacred Journey of Dementia" (which was not a religious focus, but a focus on our common humanity) - and it was a fantastic experience, great team - though I was the only person who knew them all - We had a Memory Cafe all day at the conference, and used the volunteers from those three church’s Memory Cafe leadership teams to host the conference cafe - and be volunteers for other aspects of the conference, building a real community of those who were growing in their compassion and knowledge about dementia.

Erie, NY: Don’t let volunteers take leadership roles until you are confident they have real understanding about dementia and the necessary skills to make everyone feel successful (initially many think they do, but tend to “do things for” the care receiver.

• Problems you’ve had.

Asheville, NC: MARKETING! Although we have had wonderful attendance most of our cafes, we know there are many more people out there who would enjoy this - and come. its a challenge. We live in an area known to be a draw for retirees -- so we have the population, but the cafes are run by volunteers and have no marketing experience and not many ideas. they are faithful to the event, but could use help with easy ways to do outreach. Also most volunteers are seniors themselves - trying to reach out to seniors, so the social media network is not well used by any of the above.

Erie, NY: Low attendance. We miss our “regulars” when they no longer attend as they’ve moved on to a higher level of care or have scheduling conflicts with their adult day program. Caregivers want nice crafts, not childish throw away things, it’s a challenge to make it work for both the caregiver and care receiver and not cost much. Sometimes it works well when
volunteers help care receivers with the crafts one on one and the caregivers have fun on their own. The caregivers don’t think twice about what their loved ones are doing, they are confident he/she is having a good time. We use more volunteers than we originally anticipated – both the caregivers and care receivers like the attention and appreciate direction, companionship and encouragement.

Lebanon, NH: Just the space issue, really. Plus, the students are on break for 2-3 meetings a year. The guests definitely miss the students when they are gone!

Minneapolis, MN: None at all. Everyone is so appreciative. They tell us all the time if the get together was offered every day they would come!

Richardson, TX: We haven’t had much success, even in our most successful Cafe, in getting volunteers to assume leadership of the group. The original team that developed the Cafe cannot continue to facilitate every meeting and we're not yet sure how we will solve this issue.

Sacramento, CA: Homeless guy keeps trying to "help me", I let him help till guest arrive than I say comeback at 4pm and make a plate of food, after the guests have eaten. (boundary). Not a problem for me, but Bill peed on self and his wife was embarrassed-I said hey, he wandered away and did it out of sight, pretty good and pants dried fast…told her we are all here for her and Bill.

• And anything else you’d like us to pass along.

Asheville, NC: We plan to bring the memory cafe teams together in the fall for a 'kick-off' to get everyone re-energized for the new year - fall, winter spring. - which will continue to cultivate and develop teams of people in the community who are dealing with people with dementia in a new and more respectful way.

Santa Fe, NM: Our caregivers and their family members spontaneously formed a walking group in the mornings. They all met at a designated place and time, walked some and then went to breakfast together. For a while they would also meet on a regular basis to make art.

Murfreesboro, TN: We’ve kept meeting at the same cafe that serves only lunch (11am-2pm). We arrive at 2pm and our attendees order a dessert and beverage. This gives the restaurant a little business and us an entire room. This café also supports the Alzheimer’s Association by lending the room free of charge and displaying Alzheimer resources and donation can. It helps to have 2 facilitators to play off one another’s energy and it is also helpful to have things to offer, e.g., readings, riddles, word games, proverb completion, etc. but then let the conversation evolve and flow if attendees would like to tell a memory. In future we might do a craft together. Certainly we would like more music. We end sessions by each person saying something to the person seated to their right that will really “make their day” to end on a positive note.
**Erie, NY:** Most of the care receivers attending our Memory Café are male – not what we expected – so we need keep that in mind as we plan the agenda.

**Richardson, TX:** Our original Café in Richardson Texas was an immediate success and continues to have a strong core of regular attendees, with new couples attending on occasion. It is strictly a social engagement program. However, the other 3 that followed this Café have not been as successful. We are considering moving toward the European model by including at least some education/information as part of our meetings. The problem is that we are not attracting the people we hoped to serve, i.e., couples where one has a diagnosis of dementia. The people who come are looking for a support group, local resources, education and information about the disease.

**Albuquerque, NM:** Our emphasis is 4 fold-- physical exercise, mental exercise, vascular health, and social interaction in some form or other at most meetings. We have 15 minutes of singing from an outside source, some joint singing of familiar songs, a trip down memory lane--some objects of the past to rekindle thought and conversation, a time of "what was good this month" so both caregiver and person with dementia can participate if they desire, and some videos that go along with a topic that is being or has been discussed. Trying to find a good balance to serve both caregiver and their loved ones is a goal for us. Upcoming topics include chair yoga, a short conversation with a speech and language pathologist, an afternoon in "Texas" with songs and videos of that state, and an afternoon with therapy dogs.

**Sacramento, CA:** My focus is "Be here now"...in the moment, the purpose is today and making our get together a bit special and folks leave w/ smiles/ also now I have trouble getting them to leave, they all want to help clean up & continue talking.

Volunteers: I have recruited the gero-club from Sacramento State. I am making a donation to them for helping run games & register guests. Next week will have a swim BBQ for the helpers at my house. If you go a little out of your way, volunteers know you appreciate them and it is hard to focus on them at the Café.

**Lebanon, NH:** I really hope this gets through to people. It's such a great program! Encouraging people to think outside the box in starting their own Café is important as well - find a cool location, look for fun projects, look for a unique set of volunteers. The sky is the limit.