

The Alzheimer's Café Model

Steps to Success



Friendships blossom at the Alzheimer's Café at the Frye, Frye Art Museum, Seattle WA. Photo: Olli Tumelius

Alzheimer's Café How-to Guide for Washington State Steps to Success

Introduction

An Alzheimer's Café, or Memory Café, is a regular social gathering for people living with dementia and their loved ones in a comfortable community setting like a café or coffee shop. Developed in the Netherlands in 1997, the Alzheimer's Café concept came to Washington State in 2010 when Seattle's Greenwood Senior Center launched the second Alzheimer's Café in the nation. Now there are hundreds of monthly Alzheimer's Cafés around the country – and growing!

This guide aims to spread the Alzheimer's Café model to more communities in Washington State, thus expanding social opportunities for the more than 100,000 people with dementia in our state and their loved ones. Below you will find a step-by-step guide to getting started and links to additional resources. The information included is based on a review of similar efforts in other areas and key input from local Alzheimer's Café leaders.

Anybody can start an Alzheimer's Café – from social service professionals, to people in the general community like neighborhood organizers, service club members, coffee shop owners, librarians, clergy, people with dementia and their families. If you'd like to launch an Alzheimer's Café in your community, this guide is for you!

"We feel free to ask for help in the Supper Club setting and to offer it as well. Real friendship has resulted from these dinner table conversations."

> Carol C Guest at the Mill Creek Supper Club Battle Ground, WA

Alzheimer's Cafés: The Basics

What is an Alzheimer's Café, and what is its purpose?

As noted above, an Alzheimer's Café, or Memory Café, is a regular social gathering for people living with dementia and their loved ones, in a comfortable community setting such as a coffee shop or café. While some include education or structured activities, Alzheimer's Cafés primarily provide the simple joy of being together, in a welcoming, stigma-free environment.

What is it NOT?

An Alzheimer's Café is not an adult day program or drop-off respite program, it is not an opportunity for medical or professional advice, and it is not a marketing opportunity for particular agencies or services.

Who attends?

An Alzheimer's Café is open to all, but is especially intended for people living with dementia and their loved ones. Other attendees may include interested visitors, paid caregivers, staff and volunteers, or activity facilitators like musicians or teaching artists. To foster a comfortable, inviting atmosphere, people are not typically asked about their diagnosis. People with any level of dementia symptoms are welcome. If a person needs support in order to participate, they attend with a loved one or caregiver.

Where and when does it take place?

An Alzheimer's Café can take place in any comfortable community setting. In Washington State, many cafés take place in local coffee shops or restaurants. These venues are familiar, often free, and provide a warm, social atmosphere. Other successful settings include community centers, faith congregations, museums, senior centers, libraries or parks. Medical or long-term care settings are not recommended. An Alzheimer's Café usually takes place for 1.5 – 2 hours, once a month, during a time when the venue is less busy.

What happens at an Alzheimer's Café?

While the European model of the Alzheimer's Café may include educational presentations, the American model aims to give people a break from focusing on dementia. The focus is relaxed, informal social interaction. So at its most basic level, an Alzheimer's Café "agenda" can just involve arriving, taking a seat among friends, placing an order, enjoying food and socializing. Many Alzheimer's Cafés in Washington State follow this informal model. To help foster interaction, facilitated conversations or activities can also be incorporated. Examples include sing-alongs with familiar songs, seasonal creative arts, or table games.

Steps to Success

Step 1: Assess interest

Start by exploring interest among people in your community who have dementia or who are caring for someone with dementia. Chat with people informally, bring the idea up at support groups, or try a focus group or survey. You could even host a one-time "pop-up" café, to see who shows up and how they enjoy it. If you find there is interest, continue with the rest of the planning process. People with dementia and their loved ones will continue to be essential guides as you choose the venue, timing, activities, and more.

Step 2: Get first-hand experience

As you are getting started, make every effort to visit one or more Alzheimer's Cafés for yourself. At the very least, call someone else who coordinates an Alzheimer's Café and ask them to share about their experience. With this knowledge in hand, you'll have a clear vision of the model and feel confident moving forward.

Step 3: Reach out to partners

Alzheimer's Cafés benefit from having more than one person or organization involved in planning and coordination. By working with partners that already play a well-known and respected role in your area, you increase your potential network and help build credibility. Sample partners may include senior centers or other senior service non-profit organizations, community centers, libraries, YMCA's, museums, Alzheimer's organizations, health and wellness organizations and faith communities.

Some Alzheimer's Cafés have a steering committee that plans and promotes the event. Others may be offered in partnership, or offered by a lead organization with help from a few other organizations and volunteers. Consider who in your community might be interested in helping out, whether with planning, staffing or publicity. If you need funding, for-profit senior care providers are often happy to play a role as sponsors.

"Alzheimer's Cafés are especially beneficial to people who have been newly diagnosed with Alzheimer's and their caregivers. As you interact with others, you can find out what they have gone through and learn what to expect, in a friendly, informal atmosphere."

> Bob W, Dementia Action Collaborative Member Guest at Tacoma area Alzheimer's Cafés

Step 4: Choose a venue

An Alzheimer's Café can take place in any comfortable community setting. The best venue is a place that has a welcoming atmosphere, good parking and accessibility, and times of day that are less busy. You can get creative based on the unique features of your community. Many Alzheimer's Cafés in Washington State happen in an actual café or coffee shop. These venues naturally provide a stigma-free, uplifting social setting. Plus, they will often host for free (beyond the cost of items ordered).

Around the country, other successful models exist such as hosting an Alzheimer's Café in a museum, faith congregation, library, senior center or park. In order to promote a relaxed social atmosphere, medical or senior care facilities are not recommended.

When choosing a venue, here are some things to keep in mind:

- a. Special features of your community and the interests of those attending. Is there a local place people love to go? Are you appealing to particular ethnic or cultural groups?
- b. Plenty of parking nearby.
- c. Public transportation available.

- d. Accessible building, seating and restrooms, with space to stow some walkers.
- e. Not too big or too small. Seating for up to 30 people, and enough space to move around if people want to mingle a bit.
- f. Safety. Good lighting, no obvious fall hazards.
- g. Comfort. Comfortable seating, good acoustics, warm atmosphere.
- h. Ability to adjust volume on piped-in music (where applicable).
- i. Affordability. The vast majority of Alzheimer's Cafés are free, beyond any menu items ordered. Choose a venue with low-cost menu items, and one that does not require a purchase.

Beyond the Coffee Shop: Alternative Venues

While cafés and coffee shops work great, other venues can bring their own benefits. Below and on the next page are two examples—a museum, and a library.

Frye Art Museum, Seattle, WA

The Frye Art Museum has a long history of serving people with dementia and their loved ones through arts engagement programs. An Alzheimer's Café seemed like a natural next step, with the potential to combine the creative arts and social connection. The Alzheimer's Café at the Frye includes an optional gallery tour, followed by time together in the on-site café. "The pre-café gallery tour adds a special draw to our Alzheimer's Café. The discussion about a work of art provides a shared experience which enhances the social connection guests enjoy in the café."

> Mary Jane Knecht Manager, Creative Aging Programs

"The Alzheimer's Café brings so much joy to me and my sister. She may not contribute to the art discussions, but she does share her thoughts with me. She enjoys the variety each month, and I know the socialization keeps her mind active."

> Patricia K Guest, Alzheimer's Café at the Frye



"Libraries serve everyone in the community, and we have an obligation to develop programs appropriate for an aging population. With the growth in Alzheimer's disease, our Memory Café feels very worthwhile."

> Beth Helstein Volunteer / Outreach Coordinator

San Juan Island Library, Friday Harbor, WA

Staff at the San Juan Island Library found they were increasingly serving a role as a welcoming, safe space and resource center for people with dementia and their family members. When they discovered that colleagues around the nation were launching Alzheimer's and Memory Café models within libraries, they jumped on board. They pioneered Washington's first Memory Café in a library setting in March 2017. To learn more about how libraries can get involved, see <u>www.ascladirect.org/interest-groups/alzheimers-</u> <u>related-dementias-interest-group/</u>.

Step 5: Choose a day and time

Alzheimer's Café gatherings typically last for 1.5 – 2 hours, on a monthly basis. Timing is an important aspect of your café's success. While you can choose any day or time, holding a café either too early or too late may prevent some people from attending. It is also best to choose a time of day that your venue tends to be quieter or less busy. Finally, try to coordinate with other Alzheimer's Cafés in your area, so you spread out the offerings over a month on different days of the week or different times of the day.

Step 6: Decide what you want to do at your café

Your Alzheimer's Café can involve just informal socializing, or also include structured activities that facilitate interaction. In the Seattle area, even the Alzheimer's Cafés that are primarily social often include a brief

(15-20 minute) sing-along using familiar songs. This can build a sense of camaraderie and lift people's spirits. Many Alzheimer's Cafés across the country incorporate other elements like seasonal creative arts, guided table discussion, or interactive games.

Talk with the people in your community who expressed interest in an Alzheimer's Café to get feedback on this topic. If you haven't already, try to visit one or two existing Alzheimer's Cafés to get ideas. While planning your agenda, think carefully about what will be appealing and comfortable to people with varied abilities and interests. Keep the goal of social engagement in mind, and let guests be your guide over time.



Café guests David and Daphne Jones lead singing at the Columbia City Alzheimer's Café. Photo: Full Life Care

"It can be a unique challenge to create an experience that stimulates and delights everyone. Lately we've been including table question cards that encourage people to connect in small groups. Folks with mild dementia, family members and volunteers can act as table hosts, helping the conversation flow along."

> Amy Maguire Peet's on Green Lake Memory Café Coordinator Seattle, WA

Step 7: Locate, train and clarify roles for staff, volunteers, and/or business employees

a. Staff:

An Alzheimer's Café requires at least two staff people, whether paid or volunteer. One of these staff should be consistent each month and thus often plays the lead role as host.

The host is responsible for set-up, welcoming people, facilitating informal interaction, and ensuring a smooth, safe and successful event for all. While they may be a volunteer, this person is typically someone who works for one of the partner organizations (for example a social worker, program facilitator, activity coordinator, or anyone with experience interacting with people with dementia). Successful hosts are often people who enjoy socializing and helping others connect with each other. A working knowledge of memory loss resources in the area is also helpful.

The other staff person is often a volunteer and supports the host by providing assistance in any area as needed. This role does not need to be fulfilled by the same person each month, but again it is ideally someone who enjoys creating a welcoming atmosphere. Training for these roles can include familiarizing the staff people with the Alzheimer's Café model, having them visit another Alzheimer's Café in the area if possible, sharing safety and emergency procedures, and reviewing tips for communicating with and supporting people with dementia.

b. Volunteers:

Other volunteer roles may include helping with set -up, sign-in, or activities, making reminder calls, or checking back in with new attendees. Training of volunteers will depend on their background and role, but it will be helpful to provide them the same communication and support tips.

c. Business employees:

If you are holding your Alzheimer's Café at a restaurant, coffee shop, or other very public venue, try to provide at least basic dementia training to staff who will be interacting with guests.

You will also want to discuss event logistics with the staff so everyone is on the same page about roles, and what will happen before, during and after the Alzheimer's Café event.

Topics to discuss may include:

- Menu: If a restaurant has a long or complex menu, suggest creating a shorter one for the event, with a brief selection of items from the main menu. See below for an example.
- Service: Decide whether participants will order at a counter or at their tables. If at tables, alert servers that guests may move around and socialize, so it will be useful to keep track of orders by name rather than seat location.
- Seating: If you need a special seating arrangement, discuss the layout and who will do set-up.
- Signage: Posting signs on the day of the event helps people find their way and builds awareness among other community members and customers. Decide who will make and post signs.



Modified menu, Mill Creek Supper Club

"For some guests, a photo is easier to understand. With this menu, a person can just point to what they want, rather than a loved one ordering for them. It's a subtle form of empowerment."

> Shanti Potts Co-organizer, Mill Creek Supper Club Battleground, WA

Step 8: Set a budget

If your Alzheimer's Café will take place at a coffee shop where people will be paying for their own order, and if you find a host and support staff who can play these roles as part of their regular job or as volunteers, your costs may be minimal to none. However, potential budget items could include rental fees for the venue, staff stipends, printing, decorations, food, activity materials, or paid advertising.

Create a budget for yourself and a plan how you will secure the necessary funds. This could include grants and donations, sponsorship by for-profit agencies, or in-kind donations. For example, a sponsoring agency might provide funding for staff time, or members of a faith community might donate coffee and treats.

Step 9: Gather materials

Your minimum required materials may include a sign-in sheet, pens and nametags. Depending on where you hold your Alzheimer's Café and the activities you incorporate, you may also want to purchase decorations, refreshments, and activity supplies.

Step 10: Spread the word

When you have a launch date, create a flyer, then work with your partners to distribute it to support groups, senior service agencies, community centers, faith congregations, healthcare agencies, service clubs, libraries or other local venues. Ask these organizations to include the information in their newsletters and websites. Send a press release to the local paper. Register your café at the Washington State listing (www.alzcafes.org) and the national listing (www.alzheimerscafe.com).

Marketing is an ongoing process, as there will be turnover in attendance over time. Maintain a mailing list of contacts to whom you can periodically reach out. Consider inviting referral sources to come and visit the Alzheimer's Café so they have a better idea what it's all about. Pursue additional media coverage through TV and newspapers when opportunity arises.

To maintain ongoing attendance, use sign-in sheets at each Alzheimer's Café, and do reminder calls or emails a few days before each gathering.

Step 11: Launch your café!

An Alzheimer's Café is a drop-in program, with no registration required. On the first day, you may have just a few people show up, or a large group. Be ready to add in a few chairs if needed, or to bring the group closer if there is a small turn-out.

As people arrive, welcome them warmly, invite them to sign in and create a name tag. Help set the tone for an uplifting social event – introducing people to each other, reinforcing any connections people already have with each other, and orienting people to the space and agenda. First time guests may be feeling quite hesitant. Relieve anxiety by making it clear what is happening and what is expected – guiding people to their seats, pointing out the menu, etc. After the majority of people have arrived, the host may give an overall welcome and share the basic agenda (whether that is to eat and socialize, or to do an activity together).

As the event moves along, the host continues to help foster informal interaction. Toward the end of the event, the host thanks everyone for coming, and may make announcements about upcoming community events.

Step 12: Evaluate and adjust over time

Regular attendees are a rich source of information about what is working or not working at your Alzheimer's Café. Seek feedback not only before you start your café, but all along the way. Consider using a basic satisfaction survey periodically. You may also want to conduct more in-depth interviews from time to time, to get a sense of what else could be improved.

Alzheimer's Café or Memory Café?

Many communities use the name "Alzheimer's Café" because it was the term for the original model in the Netherlands, and as a way to build awareness and challenge the stigma often associated with the word "Alzheimer's."

Others prefer the name "Memory Café," considering it to be more inclusive of other conditions and potentially less intimidating. While these two options are by far the most common, some communities choose other names altogether, like "Caring Café," "Time Out Café," or more.

Any of these work fine as long as you make it clear what the café is all about, so choose the best fit for your community!

"The world of a caregiver can become very small. Friends stay more distant since they are doing other things you no longer can do with them. So to be able to go out for a great restaurant meal with a group of others going through many of the same things as you is really a treat!"

> Mary S, Guest at the Mill Creek Supper Club Battle Ground, WA



Alzheimer's Café at the Frye. Frye Art Museum. Photo: Olli Tumelius

"What we like about it is the singing – the singing is a big, big part. And the socializing with other people. That's really important." Alice & Paul P Guests at Seattle area Alzheimer's Cafés

Additional Resources

- For a list of Washington State Alzheimer's Cafés, see <u>www.alzcafes.org</u>. Contact any of these café organizers if you'd like to visit.
- For a national registry, see <u>www.alzheimerscafe.com</u>.
- For an excellent overview of Alzheimer's Cafés, including templates for planning, marketing, budgeting, outreach, evaluation and more, see the Massachusetts Memory Café Toolkit: www.jfcsboston.org/
 Portals/0/Uploads/Documents/Memory%20Caf%C3%A9%20Toolkit/Massachusetts%20Memory%20Caf%C3%A9%20Toolkit.pdf.