

The Nuts & Bolts of Starting an Alzheimer's Café



A Manual

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Table of Contents

I. What is an Alzheimer’s Café?..... 3

II. History..... 3
a. The First Alzheimer’s Café and The European Model
b. How it came to the United States

III. Why we chose to start a Café..... 3-4

IV. Starting a Café..... 4-5
a. Developing Partnerships
b. Location of your Café
c. Marketing your Café
d. Budget

V. How to run your Café—Timing and Practical Considerations.... 5-6

VI. Café Facilitation—Day of Logistics..... 6

VII. Important Sensitivities..... 7

VIII. References..... 7

IX. Sample Alzheimer’s Café flyer8

I. What is an Alzheimer's Café?

Alzheimer's Cafés acknowledge that people living with Alzheimer's disease and their caregivers often face isolation, public judgment, criticism, and stigma because of the unusual behaviors associated with the disease. Alzheimer's Cafés provide a safe, supportive, and judgment-free setting to enjoy a community outing together, to socialize, make new friends and connections.

II. History

Dr. Bere Meisen, a psychologist at the research center for old age psychiatry in the Netherlands, started the first Alzheimer's Café after noticing that talking about the illness, even within families, was often taboo. He understood that making Alzheimer's discussable, providing information and support would be beneficial. In 1997, Dr. Meisen launched the first Alzheimer's Café at Leiden University. He saw that café visitors found recognition and acceptance and left feeling happier. Soon people were coming from around the country to attend. Now, Alzheimer's Café programs are established in a number of European countries. The first café in the United Kingdom started in 2003. Canada's first program was launched in Nova Scotia in 2011. In the United States, Café programs are in many states and fall into two broad categories, the European model and the American model.

The European Model usually includes lectures, presentations and information on Alzheimer's issues combined with a social hour. (<http://www.alzheimercafe.co.uk>) The American Model (ACA, Alzheimer's Café America) is purely a social event, giving everybody involved a respite from issues relating to the Alzheimer's disease and other dementias. Participants can enjoy art, music, poetry and socialization. Laughter and love are the cornerstones of these cafes. "By choosing to call it the Alzheimer's Café, we're determined to counter the stigma and misconceptions about these diseases. In spite of the name: Alzheimer's Café, we leave the disease at the door and celebrate the person beyond the dementia. The café is a chance for everyone to step out of their daily roles and share a positive experience in a supportive environment." ~ Dr. Jytte Lokvig

The first Memory Café (European model) opened in Colorado in 2005. The first Alzheimer's Café (American model) opened in Santa Fe in 2008. The Children's Museum of NH started an Alzheimer's Café in 2011, the first on the East Coast.

II. Why we chose to do it

The Children's Museum of New Hampshire's expertise is in creating shared joyful learning experiences and igniting a passion for lifelong learning. We know that many families are dealing with young children and aging parents. As a social environment, we offer a setting in which families can network and build connections with other families facing similar challenges. Research shows that people often find themselves feeling depressed and self-conscious after being diagnosed with Alzheimer's disease and dementia. The people in their closest network, primarily family members, may also feel the need for support. The Alzheimer's Café positions CMNH as a regular and familiar place to go where these families can connect with resources and with one another.

The intent of the CMNH Alzheimer's Café is to build families' appreciation for one another, and improve understanding and communication. The Alzheimer's Café program creates and strengthens community fabric by connecting people with common questions and linking people with needs to resources they are seeking. These relationships are sparked at the Museum but extend beyond the Café into day-to-day life helping to sustain families through the challenges they face as they address the needs of their aging parents.

This program exemplifies CMNH's goal of working with communities to meet existing needs and demonstrates an innovative, concrete way to provide community-based solutions to these problems. The outcomes we strive for through the Café include happiness, calmness, increased communication, and connectedness. While there are other programs that work toward the same end, they are designed for either caregiver support or patient therapy.

IV. Starting an Alzheimer's Cafe

a. Partners

A critical step in developing an Alzheimer's or Memory Café is to pull together a team of advisors or partners. This group can serve as a steering committee, think tank or consultants. Rather than limit partners to providers of services to seniors, strive to have members from a variety of sectors in the community to ensure more support, a wider perspective, and broader marketing. Alzheimer's and dementia can affect anyone, so you never know where support, financial or otherwise, will come. Partners can include local visual and performing artists, restaurants, Alzheimer's support group leaders and other senior providers (i.e. local chapters of ServiceLink, County

resources, Alzheimer's Association), medical professionals, members of the community.

b. Location of the café

It's important to hold an Alzheimer's or Memory Café in a non-clinical setting where attendees feel welcome. Alzheimer's Cafés are held in a variety of settings, including theatres, historic buildings, museums, libraries and restaurants. Ambiance is very important, so a nursing home or other senior facility may not be ideal since it can be threatening to persons who are in early stages or newly diagnosed with the disease; nor is it appropriate to use an Alzheimer's Café to recruit residents for your facility. No matter where the café is located, a convivial atmosphere is paramount.

One of the essential ingredients of the café concept is that caregivers and people dealing with the disease have an enjoyable outing together. The Café provides a place to find out how others deal with the illness and its consequences. Its low threshold environment allows visitors to feel at home, talk informally, and find recognition and acceptance.

Physical characteristics of the café location are very important, such as general safety, adequate parking, and easy access for people with disabilities and good signage.

c. Marketing

Attendance at the Alzheimer's Café takes time to build. Word of mouth is very important and people who enjoy the café experience can be your best marketing tool. Many seniors seem to gather their news from local newspapers, so this is an effective avenue to publicize your café. Notify senior provider professionals about your café and they will help spread the word. Invite them to visit the café so they can talk about it with colleagues and clients. The important thing is not to expect high turn out at your first meetings...it will grow!

Other marketing approaches:

- *calendar listings in local newspapers, including free papers*
- *press releases*
- *feature articles*
- *posters (in libraries, coffee shops, senior centers, etc.)*
- *radio public service announcements (including community radio)*
- *be a guest speaker on community radio programs*
- *networking through senior centers, hospitals, support group leaders, geriatricians care organizations with newsletters*
- *service networks (ServiceLink, Dept. of Health and Human Services, etc.)*
- *send monthly emails to past café attendees, service providers and network organizations, and anyone who has expressed interest in learning more*

d. Budget

Costs associated with an Alzheimer's Café are minimal; assuming the location of the café is free. Expenses fall into the categories of refreshments, entertainment and supplies, most of which can be easily donated by volunteers or local restaurants and businesses. Your time – setting up the room, facilitating the café and cleaning up afterwards – is the biggest output.

V. How is the Café run?

Cafés are usually held monthly (sometimes twice a month) at regular times, for example every first Monday of the month. The start and end times should also be fixed and consistent. Consider when holidays fall when you select your day so don't need to cancel the café, which can be confusing and interrupt the momentum of attendance. The time of day varies – morning, afternoon or evening. Each option has advantages and your choice will depend upon your café location and knowledge of your community. Your advisory committee can help with this decision.

Provide a table for general information about Alzheimer's (the Alzheimer's Association provides many wonderful resources) and local support groups. Be wary of businesses that want to attend the café – they are looking for clients. Café attendees will not appreciate being hustled for business and won't feel secure about your motives if they aren't protected from this type of intrusion.

Practical Considerations:

- *Always have refreshments!*
- *Is the temperature of the room comfortable?*
- *Is the volume of music playing too loud?*
- *Provide nametags for visitors and café staff/volunteers.*
- *Are tables and chairs arranged so that everyone can see one another?*

VI. Cafe Facilitation

Alzheimer's Café is a deceptively simple concept – people come to socialize and chat – but not easy. Think of yourself as a host/hostess of a tea or cocktail party where you don't know all the guests very well. You'll need to be comfortable meeting new people, helping them to feel welcome, making and maintaining conversation, and avoiding or redirecting the occasional minefield. This can be exhausting! It's crucial to have a team of 3 – 4 people to help facilitate the café by:

- *welcoming attendees as they arrive and create a name tag*
- *asking newcomers to sign in (get contact information)*
- *showing newcomers where to hang coats, find restrooms, have refreshments, etc.*

- *being aware of visitors who are not engaged in conversation so you can visit with them*
- *keeping the conversation going – have a list of topics in mind to bring up if there’s a lull (the weather, gardens, current events – not too political! books, movies, family heritage, grandchildren, places people have lived...)*
- *attending to a visitor who needs to talk about a personal issue or needs advice*
- *replenishing refreshments*
- *handling logistical issues - needing more chairs, for example*

Each café will develop its own personality based largely upon the visitors. At the Children’s Museum of NH, our café attendees prefer visiting with each other to any other activity. They enjoy musical performances and singing along, but after 20 minutes or so, they are anxious to get back to conversing with their café friends. You may find your café attendees are very interested in making art or singing.

VII. Most important

Persons with dementia and Alzheimer’s are at the center of the Alzheimer’s Café and everyone needs to be treated with respect and dignity. It’s crucial to include them and strive to make them feel comfortable in every way. Don’t talk about someone as if they can’t hear or understand you; nor speak to them as if they were a child.

References:

Alzheimer’s A to Z: A Quick Reference Guide
 The Definitive Guide to Compassionate Alzheimer’s Care
 by Jytte Lokvig, M. A. and John D. Becker, M.D.

The Alzheimer’s Café – a Guideline for Setting One Up
 by Bere Miesen and Marco Blom; translated and adapted from the Dutch Alzheimer Society document by Gemma MM Jones

Neighborhood Memory Café Tool Kit – developed by Sydney Farrier, LCSW, Pam Kovacs; Carole Larkin, MA CMC; Pat Sneller

