

Children's Museum of New Hampshire's
Evaluation of the Benefits of
Attending the Alzheimer's Café

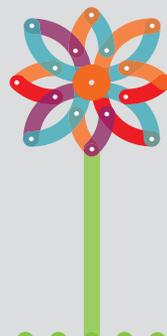
**CHILDREN'S
MUSEUM**
of NEW HAMPSHIRE





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INTRODUCTION

The Alzheimer's Café program at the Children's Museum of New Hampshire in Dover was designed to address an unmet need in the community for people caring for a loved one with Alzheimer's disease or other dementias. Due to the unusual behaviors associated with the disease, people living with dementia, their families and care partners often face isolation, public judgment and criticism.

Unlike a caregiver support group, respite or adult day program, an Alzheimer's Café model engages people affected by the disease and their care partners together in a social setting. We wanted to provide a safe, supportive and judgment-free setting where care partners and those affected by the disease could enjoy an afternoon in the company of people on the same journey. With the help of volunteers who welcome visitors and keep everyone engaged in conversation, we hoped that families would feel comfortable, calm and happy, make new friends and discover helpful resources.

We noticed that Café attendees seem to enjoy themselves, and often form friendships that extend beyond the museum. Although Cafés are not for patient therapy, we observed they can have a beneficial affect, and that's what we wanted to study.

With the help of a nurse researcher and a graduate nursing student, a study was created using multiple methods of collecting data. In this report, we will share the results of the study, which highlights the benefits of coming to an Alzheimer's Café at the Children's Museum from the perspective of those who attend it.



*"I like the friendly, social atmosphere. We have friends here who are in the same boat. Caregivers need support just as anyone."
-Café Attendee*



THE CHILDREN'S MUSEUM OF NEW HAMPSHIRE

Founded in 1983, the Children's Museum of New Hampshire is a vibrant organization that shapes communities by celebrating children's and families' creativity and learning. Our mission is to unlock children's creative potential by sparking imagination, supporting inquiry, and scaffolding learning. The Children's Museum is one of the most visited cultural and educational attractions in New Hampshire with 93,000 visitors annually. In 2008, the Museum relocated from Portsmouth to Dover following a \$3.5 million capital campaign. The organization transformed Dover's historic armory into an accessible, state-of-the-art facility that was awarded Silver LEED Certification by the United States Green Building Council. The Museum offers 19 exhibits, facilitated programs in arts, science, and literacy, workshops, and camps in a social learning environment that layers self-guided discovery to engage visitors in 21st century skills. Nearly 28% of visitors are admitted through free or reduced admission programs designed for families in challenging circumstances.



THE ALZHEIMER'S CAFÉ at the Children's Museum of NH

Since October 2011, The Children's Museum's Alzheimer's Café, welcomed multiple generations of families living with Alzheimer's disease and forms of dementia, along with their care partners into the Museum on a monthly basis. Families are invited into the lively, colorful, multi-generational Museum on the 3rd Thursday of each month from 2-4pm. There is no cost to attend.

One of the essential ingredients of the Café is that care partners and people dealing with the disease have an enjoyable outing together. The Café provides an informal place to find out how others deal with the illness and its consequences. The low threshold environment allows visitors to feel at home, talk informally, and find recognition and acceptance. Persons with dementia and Alzheimer's are at the center of the Alzheimer's Café, and are treated with dignity and respect.

The Museum received the 2012 *Leaders in Innovation Award* from the New England Museum Association in recognition of the uniqueness of the Alzheimer's Café program.

*"[The Café] is like a window to my future, and much more informal than a support group. It's lighter and it helps me prepare for where I'm heading."
-Café Attendee*



HISTORY OF THE CAFÉ MODEL

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 throughout the globe in Europe, Australia, and North America. 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 can be found in many states and fall into two broad categories, the European model and the American model. The European Model usually

combines a social hour with lectures, presentations and information on Alzheimer's issues, whereas the American Model (Alzheimer's Café America or ACA) is a purely social event that gives everybody involved a respite from issues relating to Alzheimer's disease and other dementias. Participants can enjoy art, music, poetry and socialization.

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

"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, founder of the first Alzheimer's Café in Santa Fe, NM



WHAT WE STUDIED

The primary objective of the study was to determine if our Café was perceived to be beneficial by those who attend. We also wanted to identify specific benefits, and learn what improvements could be made, based on participants' views. As research is limited, we hoped to add to the body of knowledge regarding this community-based, non-pharmacological approach to supporting people affected by dementias, their family and friends. Finally, we anticipated that armed with data indicating the benefits of an Alzheimer's Café, more Cafés would emerge for families to visit.

The Director of the Café initiated the study and called upon a nurse researcher and a graduate nursing student to join the research team. Together we designed a three-pronged approach to gather data from participants comprising observations, surveys and interviews. The Human Subjects Institutional Review Board (IRB) at Keene State approved the study protocol, and after researchers completed research ethics training online through the Collaborative

"Some of the good things that have happened since coming to the Café are the building up of community and learning about different people and what they do. I like seeing the happiness of the person I'm caring for, seeing them comfortable and not afraid; keeping alive those cognitive skills is important."

-Café Attendee

Institutional Training Initiative, Keene State approved certification to conduct the study. Café attendees and volunteers provided informed consent to participate in the study.

Data was collected over a period of four months from those who regularly attend the Alzheimer's Café at the Children's Museum of NH. (see figure 1)

FIGURE 1

DATA COLLECTION TOOLS AND SAMPLE SIZE:

TOOLS/METHOD	ATTENDEE	SAMPLE SIZE
Questionnaire	Person with dementia	2
	Care partner	19
	Staff/volunteer	1/5
Interview	Person with dementia	3
	Care partner	8
Observation	Person with dementia	7

THE TOOLS WE USED

OBSERVATIONS:

We discovered an observation tool used in a study in Cincinnati to gauge the emotional affect and attitude of persons with dementia who attend the Café (figure 2). The tool helped us to look at six domains of well-being.

FIGURE 2

INDICATORS FOR EACH OF THE DOMAINS OF WELL-BEING	
Domain of well-being	Indicators*
INTEREST	<ol style="list-style-type: none"> 1. The participant shows interest in other participants once the activity is underway. 2. Without prompting, the participant offers support of a peer's participation in an activity by making eye contact, smiling, looking toward the person, or acknowledging the person verbally, one or all of these. 3. The participant acknowledges support from peers by eye contact, smile, verbalization, extending hand or all of these.
SUSTAINED ATTENTION	<ol style="list-style-type: none"> 1. While engaged in the activity, the participant has sustained attention for a period of 10 minutes. 2. The participant requires verbal prompting or cueing during the activity to sustain the project or activity. 3. The participant initiates and engages in conversation with peers or facilitator and then returns to activity and refocuses.
PLEASURE	<ol style="list-style-type: none"> 1. The participant has relaxed body language, smiles and laughs during the activity. 2. The participant verbalizes a sense of pleasure with phrases such as: "this feels good," "this is relaxing," or in the verbal expression of unintelligible phrases such as "ooh", "aah", accompanied with smiles, crinkling of eyes or relaxed facial expression.
NEGATIVE AFFECT	<ol style="list-style-type: none"> 1. The participant is angry during the activity. 2. The participant is agitated during the activity. 3. The participant verbalized feeling anxious ("I feel nervous," "I am jumpy," "I feel funny today").
SADNESS	<ol style="list-style-type: none"> 1. The participant is sad during the activity as evidenced by one or all of the specified indicators. 2. The participant verbalizes feeling sad at some point in the activity.
SELF-ESTEEM	<ol style="list-style-type: none"> 1. The participant nonverbally expresses pride in participating and completing a project by smiling, nodding happily, tearfulness, clapping. 2. The participant verbally expresses satisfaction after completing a successful activity. 3. The participant verbally expresses pride through expressions of reminiscence.
NORMALCY	<ol style="list-style-type: none"> 1. The participant verbally expresses feeling good about being in a group activity, which may be expressed as "I feel normal again," "I don't feel so alone," or other positive statements. 2. The participant nonverbally expresses social normalcy evidenced by one or all of the following: interest in others, sustained attention to task, relaxed body language; if there is an affective reaction, that reaction does not escalate or perseverate. 3. The participant, when joining or leaving the activity, chats openly with another, shakes hands, pats back, says or nods good-bye.
<p>*Each indicator is rated using the following scale for each 10-minute observation period: 4 = Always, 3= Most of the time, 2= Some of the time, 1 = Rarely, 0 = Never.</p>	

QUESTIONNAIRES:

We developed a questionnaire for participants to rate their satisfaction with components of the Café. We also asked for zip codes to determine how far people traveled to attend the Café, whether or not it was their first visit, and who accompanied them (see figure 3)

A separate questionnaire was designed for the Café volunteers consisting of four open-ended questions. (see figure 4)

ALZHEIMER'S CAFÉ SURVEY QUESTIONNAIRE - 2015

FIGURE 3

1. What is your zip code?
 2. Is this your first visit to the Café?
 3. What is your relationship to the person who accompanied you?
 4. How long ago did he/she receive a diagnosis of Alzheimer's or dementia?
 5. Please rate the following by circling your response below:
- | | | | | |
|-------------------------|------|------|------|-----------|
| Volunteers and staff | Poor | Fair | Good | Excellent |
| Connecting with others | Poor | Fair | Good | Excellent |
| Getting new information | Poor | Fair | Good | Excellent |
| Meeting new people | Poor | Fair | Good | Excellent |
| Music | Poor | Fair | Good | Excellent |
| Animal visits | Poor | Fair | Good | Excellent |
| Refreshments | Poor | Fair | Good | Excellent |
| Overall visit today | Poor | Fair | Good | Excellent |
| Other | Poor | Fair | Good | Excellent |

6. Please complete the following statement by circling your response below:

Since coming to the Alzheimer's Café, I/we...

Discovered new resources	Agree	Disagree	NA
Felt comfortable and relaxed	Agree	Disagree	NA
Have become more involved in our community	Agree	Disagree	NA
Don't feel so alone	Agree	Disagree	NA
Feel happier after attending	Agree	Disagree	NA

Thank you!

QUESTIONS FOR STAFF/VOLUNTEERS - 2015

FIGURE 4

1. What is your role at the Café?
2. How is the Café beneficial to you?
3. What do you perceive are the benefits of the Café to attendees?
4. What do you like most about the Café?
5. How could the Café be more enjoyable?

INTERVIEWS:

The third tool was used for in-person interviews conducted during the Café, but in a separate room at the Children's Museum. Persons with dementia were interviewed together with their care partner and everyone was asked the same five questions (See figure 5) and their answers were transcribed. Two members of the research team read the transcriptions and identified common themes, and then we compared notes and came to a consensus on the themes from the interviews.

ONE-TO-ONE (10 TO 15 MINUTE) INTERVIEW WITH GUIDING QUESTIONS

1. What do you like the most about the Café?
2. What would you like to see more of in the Café?
3. What are some good things that have happened when you come to the Café?
4. What are some things that have been "not good" about the Café?
5. Would you tell others to come to the Café? Why or why not?

FIGURE 5

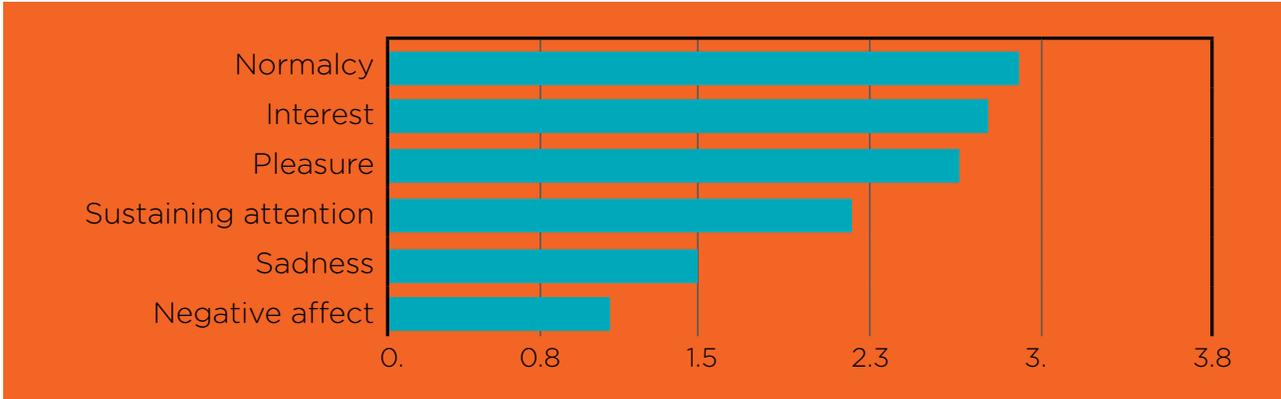
THE DATA WE COLLECTED

OBSERVATIONS:

Social normalcy was the most frequently observed domain of well-being indicated by shaking hands, patting someone’s back, and nodding good-bye or engaging in other socially acceptable ways. Indications of feeling *pleasure*, *sustaining attention*, and showing *interest* and *self-esteem* were also observed most of the time. *Sadness* or *negative affect* (agitation or anger) were rarely observed. (see figure 6)

“I made some new friends. That’s a great thing - I got to understand the progression of Alzheimer’s in various stages. It gives me a better understanding.”
-Café Attendee

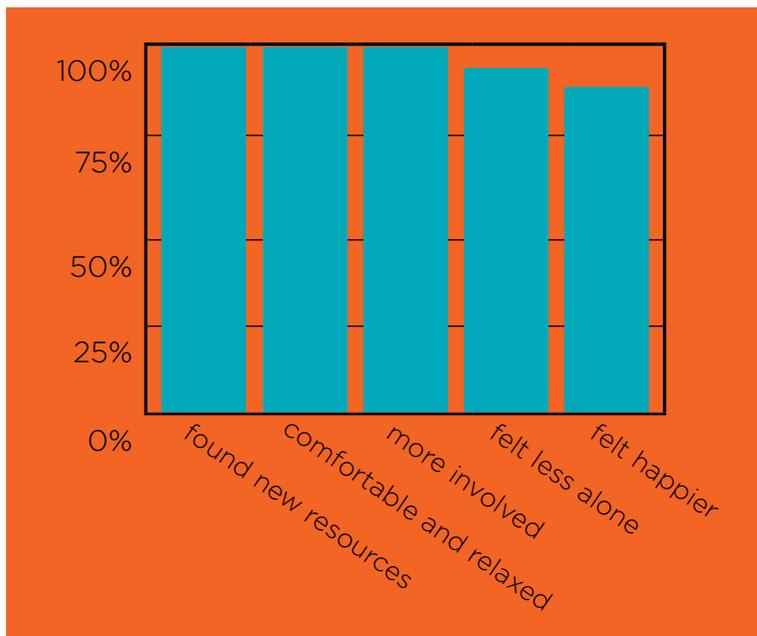
FIGURE 6



QUESTIONNAIRES:

Attendees - Using a Likert scale, all of the care partners agree that since attending the café they found new resources, felt more relaxed and were more involved in the community. The majority (90%) agree that they feel happier after attending the Café. Some drove up to 35 miles to attend the café; most people traveled an average of 10.4 miles. Two participants with dementia completed the questionnaire and both agreed that they feel more relaxed and happier after attending the Café.

SINCE COMING TO THE CAFÉ, I/WE HAVE



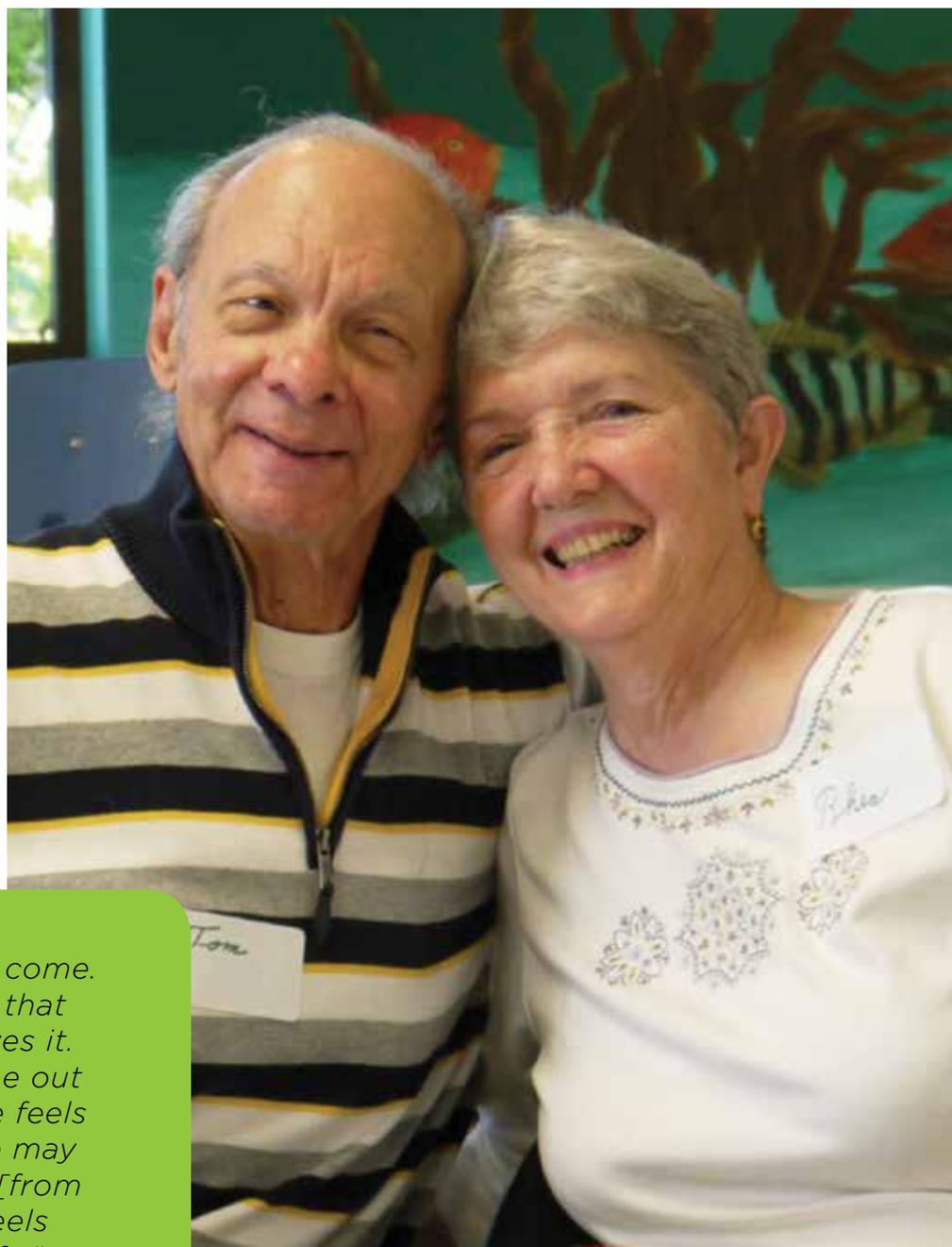
Volunteers - A qualitative analysis of the responses revealed common themes of enjoyment at seeing attendees feeling content and happy and creating new friendships. The volunteers especially like the nonjudgmental feeling of the café, and that most attendees smile a lot and seem relaxed. They also feel good about learning more about Alzheimer’s and being able to help the families who attend the Café. Volunteers said they’d like to have music or other entertainment more often at the Café.

FIGURE 6

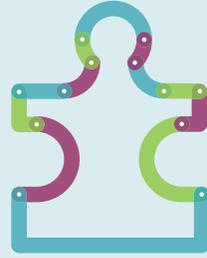
INTERVIEWS:

Three people with dementia and eight care partners agreed to be interviewed. The common theme of what the people with dementia like is “the familiar faces and the smiles”. What they like best about the café is that, “it makes me happier.” When asked if they would recommend attending the café to others, they responded, “Yes, because there are people like me.” Care partners like the friendship at the Café, and that it’s an outing that both partners enjoy. They like seeing their loved ones happy, meeting other people and learning from others’ experiences. They also enjoy being socially engaged and building a community. Several care partners expressed concern that the Café was becoming too crowded and noisy. They unanimously said they’d recommend attending the Café to others because it’s “cheerful, welcoming, and friendly”.

“We always tell people about the Café. I think it is very important that both patient and caregiver have an outlet to be with other people. It is somewhat comforting to know you are not alone.”
-Café Attendee



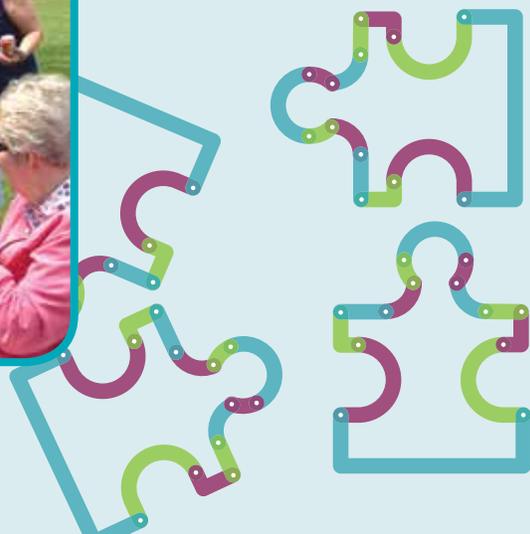
“My husband loves to come. He has people here that he knows and he loves it. It cheers him up to be out with other people; he feels isolated at home. He may go home exhausted [from the Café] but he feels better about his life.”
-Café Attendee



WHAT WE LEARNED

Several common themes emerged across the various data collecting methods about the perceived benefits of attending an Alzheimer's Café. The Café is perceived as a fun, relaxed place that promotes a sense of normalcy, a non-judgmental environment where both care partner and care partner feel happier and find a strong sense of connectedness to others and to a community. The same relaxed feeling was reported by staff and volunteers who share the observation that the Café is a place where care partners find an opportunity to relax and feel happiness at seeing their loved one happy. Significantly, unanimous whole-hearted agreement came from both partners who say they would recommend the café to others.

One notable finding is that people with dementia reported that what they liked about coming to the Café was seeing "familiar" and "good" faces. Despite the short-term memory loss associated with dementia, repeated visits with people whom they have seen before seems to have a positive effect. Those who attend often seem to feel a sense of inclusion and camaraderie.



GOING FORWARD

Based on what the Café attendees told us throughout the evaluation study, we will continue to provide an atmosphere that is reassuring, pleasant and relaxed. We intend to schedule more musical performances and other recreational activities. The size of the Café is restricted by the space available at the Children’s Museum, but we’ll make every effort to mitigate the feeling of being crowded.



The Children’s Museum’s Café is consistently well-attended, (15 – 25 people per month); and while this data sample is not large, the use of multiple collection methods strengthen the findings. We recognize that this evaluation project studied only one Café and we cannot say that attendees of other cafés would have similar perceptions. We welcome the opportunity to share the evaluation tools with other café programs that wish to do their own evaluation study.

“The Café is gentle. It is a place to solve problems. The #1 requirement is to show up.”
-Café Attendee

CONCLUSION

The social, person-to-person encounters at the Alzheimer’s Café generate a feeling of well-being and contentment for both partners, and can renew and strengthen their relationships with other people at a time when connections are fading. We encourage others to replicate this non-medication, non-invasive, low-cost approach that can benefit people with Alzheimer’s disease and their care partners. It is our hope that by sharing these evaluation results, more cafés will be established, more care partners will attend, and more families will experience a measure of respite from the inevitable march of the disease.



RESOURCES:



RESOURCES ABOUT ALZHEIMER'S

Good resource site for caregivers:

www.caring.com

Alzheimer's Association:

www.alz.org

Alzheimer's Foundation:

www.alzfdn.org

ADEAR, Alzheimer's Disease Education and Referral Center:

www.alzheimers.org

The Alzheimer's Speaks Website and Resource Directory:

www.alzheimersspeaks.com

www.blogtalkradio.com/alzheimersspeaks

Changing Aging Blog:

changingagingblog.org

American Society on Aging:

www.asaging.org

National Council on Aging, NCOA:

www.ncoa.org

Excellent daily online newsletter:

alznews.com

Sites for caregivers, including chat rooms:

www.caring.com

www.ec-online.net

ARTZ, Artists for Alzheimer's:

www.artistsforalzheimers.org

Buck & Buck Designs, Specialty clothing:

www.buckandbuck.com

S&S Healthcare crafts catalog:

www.ssw.com

Medical Identification jewelry:

www.medical-id.com

Safe Return (Alzheimer's Association program):

www.alz.org/safereturn

Project Lifesaver:

www.projectlifesaver.org

Mayo Clinic: www.mayoclinic.com

MEDLINEplus: medlineplus.gov

NIH Senior Health: nihseniorhealth.gov

Healthfinder: www.healthfinder.gov

RESOURCES TO HELP YOU START AN ALZHEIMER'S CAFÉ

Dr. Jytte Lokvig's website: www.alzheimersatoz.com, to order *Alzheimer's A to Z, a Quick Reference Guide*, www.newharbinger.com/bookstore/productdetails.cfm?PC=316

Link for NHPR story about Alzheimer's Café with Dr. Jytte Lokvig, May 2011

info.nhpr.org/alzheimers-caf%C3%A9s-where-laughter-best-medicine

Link to NHPR story about the Children's Museum of NH's Alzheimer's Café, January 2013

www.nhpr.org/post/alzheimers-caf-unforgettable-therapy

Article in Foster's (local publication) about the Children's Museum of NH's Alzheimer's Café

www.fosters.com/apps/pbcs.dll/article?AID=/20120303/GJNEWS_01/703039953/0/SEARCH

Alzheimer's Redefined, The Atlantic Monthly

www.theatlantic.com/health/archive/2011/12/the-top-10-health-stories-of-2011/249947/#slide7

Richard Taylor's message is crucial: *Alzheimer's From the Inside Out* by Richard Taylor, Ph.D., Health Professions Press, ISBN-10: 1932529233;

Richard Taylor's newsletters:

www.richardtaylorphd.com

DVD: *Be with me TODAY* www.haveagoodlife.com

The Complete Guide to Alzheimer's Proofing Your Home by Mark Warner, *Ageless Design*, ISBN 1557532028, www.alzstore.com/alzheimers/the-complete-guide-to-alzheimers-proofing-your-home.htm

Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease by Joanne Koenig Coste Publisher: Mariner Books (September 8, 2004) ISBN-10: 0618485171

www.learningtospeakalzheimers.com/book.html

Finding the Joy in Alzheimer's. Caregivers Share the Joyful Times by Brenda Avadian Publisher: North Star Books, ISBN 0963275232,

www.amazon.com/Finding-Joy-Alzheimers-Caregivers-Joyful/dp/0963275224

Voices of Alzheimer's by Betsy Peterson, Lifelong Books ISBN 0738209627

www.voicesofalzheimers.com

Decoding Darkness, The Search for the Genetic Causes of Alzheimer's Disease by Rudolph E. Tanzi and Ann B. Parson, Perseus Publishing, ISBN 0738205265 www.amazon.com/Decoding-Darkness-Genetic-Alzheimers-Disease/dp/0738201952

And all the books by William H. Thomas, MD and Tom Kitwood. Search engine for books: www.fetchbook.info



ALZHEIMER'S CAFÉS ACROSS NEW HAMPSHIRE

Concord

CAPITAL AREA MEMORY CAFÉ

3rd Wednesday of each month from 2-4pm

Granite Ledges of Concord

151 Langley Parkway, Concord, NH 03301

Contact: 603-230-5673 or visit website www.crvna.org

Dover

ALZHEIMER'S CAFÉ AT THE CHILDREN'S MUSEUM OF NH

3rd Thursday of each month from 2-4pm

6 Washington St. Dover, NH 03820

Contact: Paula Rais 603-742-2002, or email

paula@childrens-museum.org

Durham

THE ALZHEIMER'S CAFÉ AT THE DURHAM PUBLIC LIBRARY

1st Friday of each month from 10:30am-12 Noon

49 Madbury Road, Durham, NH 03824

Contact: Nicole Moore, nmoore@ci.durham-nh.us at

603-868-6699 or Erika Lee at 603-332-1133 x203

Hanover

THE UPPER VALLEY MEMORY CAFÉ AT HOWE LIBRARY

One Saturday a month from 10:30am-12:30pm

Mayer Room, 13 South Street, Hanover, NH 03755

Contact: The Dartmouth-Hitchcock Aging Resource Center at 603-653-3460 or AgingCenter@hitchcock.org

Manchester

ALZHEIMER'S CAFÉ AT THE CURRIER MUSEUM OF ART

2nd Wednesday of each month from 2-4 pm

150 Ash Street, Manchester, NH 03104

Contact: Megan McIntyre, 603-669-6144 x113 or

mmcintyre@currier.org

MEMORY LANE CAFÉ AT BEDFORD HILLS CENTER

4th Wednesday of each month from 10am-12 Noon

30 Colby Court, Bedford, NH 03110

Contact: Shirley Gordon at 603-647-6390 or shirlgrdn@yahoo.com

Nashua

MEMORY CAFÉ AT THE NASHUA PUBLIC LIBRARY

3rd Friday of each month from 2-3:30pm

2 Court Street, Nashua, NH 03060

Contact: Carol Luers Eyman, 603-589-4610 or

carol.eyman@nashualibrary.org.

Peterborough

SUMMERHILL ASSISTED LIVING AND MEMORY CARE COMMUNITY

1st Thursday of each month from 2-3pm

183 Old Dublin Road, Peterborough, NH 03458

Contact: 603-924-6238 or visit summerhillal.com

Warner

THE ALZHEIMER'S CAFÉ AT THE TELEPHONE MUSEUM

2nd Thursday of each month from 9-11am

Downstairs in the Cloues Room, One Depot St., Warner, NH 03278

Contact: 603-456-2234 or info@nhtelephonemuseum.org

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AARP New Hampshire

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**CHILDREN'S
MUSEUM**

of NEW HAMPSHIRE

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