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Living Well with Dementia & Museums: Using Collections to Spark Reminiscences

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Living Well with Dementia & Museums: Using Collections to Spark Reminiscences

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Keywords Museum; Accessibility; Inclusion; Dementia; Alzheimer's

Abstract With conversations in the museum profession moving towards placing importance on diversity, equity, inclusion, and accessibility, in all conversations, there are many approaches to considering accessibility in museums. Particularly for the small museum, to take on a new project regarding museum accessibility also means considering any limitations in funding and personnel. How can a small museum create an inclusive and accessible environment with these limitations? One potential solution is to create a sustainable program that is designed with the existing population of museum visitors in mind. The Monroe County History Center created its Living with History programming initiative for community members living with dementia and their care partners. Using existing models for dementia-friendly museum programming, this small museum has opened its doors and collection to creating new opportunities for social inclusion in the Bloomington, Indiana community.

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Conversations in the museum profession are moving towards placing importance on diversity, equity, inclusion, and accessibility, in all areas of the field. There are many perspectives to consider. To serve a diverse visitor population, there is a vast array of enhancements and updates taking place, from accommodating physical differences to intellectual and developmental differences. Sound levels, font sizes and styles, and mapping of physical spaces are taken into account not just for exhibitions but also for special programming. While designed with particular accommodation in mind, many of these considerations are applicable to those museums that have visitors who live with dementia. With an ever-growing aging population, museums have the opportunity to serve those living with dementia and their care partners. By making simple enhancements and updates to existing programming and exhibitions, museums can reach this underserved population.

Dementia and Accessibility

Dementia, an umbrella term with over one hundred twenty diagnosed types of brain disease, affects over 5.8 million Americans.¹ As a degenerative disease that is caused by the deterioration of neurons, the brain goes through many changes even before an official

diagnosis. As dementia develops, changes in cognitive function, problem-solving, and visual and spatial relationships occur.² Sensitivity to light and loss of peripheral vision are common symptoms of dementia, as is a reduced ability to separate background and foreground noise. With these changes in the brain often come a change in mood and personality and a gradual withdrawal from work or social activities. As the disease progresses, a person living with dementia can become progressively socially isolated.

In a museum setting, addressing the changes within the brain to create an accessible environment can be as simple as adding images and arrows to wayfinding materials or subtitling videos that play within an exhibit gallery. In this regard, the changes made for increasing accessibility are often the same ones made for those living with a hearing or vision impairment. To address the social isolation that develops along with dementia, museums around the world are creating new and innovative solutions.

How Museums Can Help

No matter how a museum visitor may be described or identified,³ museums as cultural organizations are in a unique position to accommodate visitors and be a part of holistic treatment. Simply put, a person's well-being can be impacted by an interaction with a cultural experience.⁴ To shift toward social prescribing, as referred to in the United Kingdom,⁵ medical professionals in the United Kingdom and Canada are looking to museums and cultural experiences to combat social isolation and increase serotonin levels. For its trial year in 2019, the Montreal Museum of Fine Arts worked with members of the Médecins francophones du Canada to prescribe patients and their care partners museum visits as a part of their treatment.⁶ These ideas of social prescription can be applied to special programming in museums.

Programming for people living with dementia is not a new topic in museums. Like programming for those living with intellectual and developmental differences that experience sensory sensitivities, art museums have created programming for people living with dementia. The Museum of Modern Art in New York developed the Meet Me at MOMA program to create opportunities to engage with the art in the MOMA collection and to provide social engagement.⁷ In 2009, the MOMA Department of Education developed and published a modular workbook highlighting workshops used in the Meet Me at MOMA program. Without having to travel to New York to see the physical artworks, these exercises and activities can be used across the country in assisted living facilities and at home.

In the United Kingdom, the National Museums Liverpool has created a successful and robust memory program that utilizes the museum's collection of archives and objects. From these House of Memory programs, a digital app was developed with the assistance of people living with dementia to use the digitized collection of the National Museums Liverpool outside museum walls. By using this free app, anyone in the world could access or add their own objects and photos to generate conversations and reminiscences. In 2018, the Minnesota Historical Society joined the House of Memories program as the first official partner in the United States, adding their digitized collection to the application. And in May of 2019, the House of Memories program took its first steps in expanding to Singapore.⁸

The Museum of Modern Art in New York, the National Museums Liverpool, and the Minnesota Historical Society are all unique instances of serving the aging community using existing resources. These museums all have common themes in their programming for those living with dementia. Each museum is highlighting its collection in an informal educational setting. There are no set lesson plans, rather an outlined structure. This is ideal for programs designed for those living with dementia because it allows for necessary flexibility. With the changes in cognitive function seen with dementia, conversations can become stilted and tangential. A facilitator can have a guiding plan for their program but must keep in mind that the plan will get interrupted. Each museum's programming has an open structure to account for this need for flexibility.

For those programs that are hosted at the museum's facilities, it also gives those living with dementia and their care partners a respite from daily appointments and social pressures. The museum provides a safe place for everyone to gather without judgment. While each person's journey with dementia is not the same as the person sitting next to them, there is a sense of understanding and camaraderie. The museum offers these programs which can allow care partners to relax and enjoy their time rather than leading an activity or managing a schedule.

Bloomington, Indiana - A Dementia-Friendly Community

Bloomington, Indiana, has a host of organizations that contribute to being the leading dementia-friendly community in the state. Leading these organizations is the Alzheimer's Resource Service of Indiana University Health Bloomington Community Health, a department of the Indiana University Health Bloomington Hospital that provides free services to community members living with dementia and their care partners.⁹ Currently, the two Alzheimer's Resource Service staff members provide consultations, training, support groups, and a library of resources for eleven counties in the south-central region of Indiana. For local businesses and organizations, the Alzheimer's Resource Service administers a dementia-friendly business training and certification program providing basic facts of dementia and customer service techniques to accommodate visitors and their care partners. The community members that complete this training and those who use the services from the Indiana University Health offices participate in some fashion in the Dementia-Friendly Bloomington community at large.

The Dementia-Friendly Bloomington community is comprised of multiple commissions, coalitions, nonprofit organizations, and community groups. For those organizations that become certified dementia-friendly businesses, a quarterly meeting occurs where representatives can share news of upcoming projects, research, and updates on new community needs with Alzheimer's Resource Services staff. The City of Bloomington created its Commission on Aging to create public awareness opportunities for the aging community of Bloomington, Indiana. This commission focuses on community collaboration, creative aging, and dementia-friendliness within Bloomington. The Active Aging Coalition of Bloomington acts as a community support group for seniors, care partners, and community members to gather and engage with community presenters. Both the Commission and Coalition seek to highlight new opportunities in the Bloomington community to improve the quality of life for the aging community through social engagement.

Together, members of each commission, coalition, professional organization, and advocacy group in Bloomington gather to create an annual Dementia-Friendly Bloomington Conference. Rather than being a conference of healthcare professionals coming together to discuss new care techniques, the Dementia-Friendly Bloomington Conference features multiple presentations, performances, and panel discussions by community members living with dementia. The 2019 conference featured a performance by the all-inclusive dementia-friendly Sing for Joy choir and a panel discussion of three men who made remarks on their journey of being diagnosed and living with the disease. With this format, the Bloomington community commits itself to person-centered care that reaches far beyond the walls of healthcare facilities.

Living with History - A Programming Initiative

The Monroe County History Center, located in Bloomington, Indiana, approached creating special programming to support those living with dementia and their care partners. The staff of the museum sees this as an opportunity to be a resource to live well with dementia. In partnership with the Alzheimer's Resource Service of IU Health Bloomington Community Health, and support from the Community Foundation of Bloomington and Monroe County, Inc. through a community impact grant, the Monroe County History Center embarked on a one-year journey to become a part of the dementia-friendly Bloomington community through the creation of sustainable memory programming for the community at no cost.

The primary goals of the Living with History programming initiative are: to expand the capacity of the Monroe County History Center and Alzheimer's Resource Service of IU Health Bloomington Community Health to serve excluded populations, to reduce social isolation of people living with dementia and their care partners, and to broaden dementia awareness and the role of the Monroe County History Center and Alzheimer's Resource Service of IU Health Bloomington Community Health as vital and rich assets for the quality of life and well-being in Monroe County.

The Living with History programming initiative is broken down into many parts: training, memory boxes, memory lane cafes, and memory walks. First and foremost is providing staff and volunteer training. The Monroe County History Center is now a certified dementia-friendly business and continues to take steps to increase the accessibility of the center's building and create a welcoming environment for all. Each staff member and several volunteers completed the dementia-friendly business training with partners at the Alzheimer's Resource Service office, and two staff members traveled to the Minnesota Historical Society for memory program observations. Through this training, staff and volunteers are better equipped to address visitors diagnosed with the disease.

The first public offering of the Living with History programming initiative was care partner training workshops. These workshops were an opportunity for the public to learn about and experience the initiative's components. The incorporation of similar programs was emphasized during consultations with representatives from the House of Memories of National Museums Liverpool and the Minnesota Historical Society. The first workshop in May for friends and family care partners offered an educational session with the Alzheimer's Resource Service, a sneak preview of the first memory box, a guided gallery tour, and lunch. The second care partner training workshop in December attracted professional care partners

from the many senior care facilities in Bloomington to engage with the many parts of the programming initiative. Each participant received a care partner toolkit with tips and tricks of caring for personal objects that can be used in personal memory boxes, communication techniques when creating memory activities, and contact information for local resources.



Figure 1: Hilary Fleck (left), Collection Manager, and Susan Dyar (right), Director, of the Monroe County History Center pose with the first memory box.

Memory boxes were the second component of the initiative made publicly accessible. Available year-round, for a one-week rental and at no charge, the memory boxes act as a mini curated museum that can be taken home and explored at your own pace. Each memory box is themed and contains an audio box with questions available to act as prompts in a conversation. The first memory box developed focuses on the 1960s with photographs, objects, and sounds that refer to local and national events. Each object or photo has a corresponding postcard that when placed on the audio box will play related sound effects and questions to begin conversation. Memory boxes may be utilized in a group setting or one-on-one conversation and are designed to allow participants to engage with the objects as little or as much as they want.

At the Monroe County History Center, there is a dementia-friendly program once a month, alternating between memory lane cafes and memory walks. The memory lane cafes are one-hour programs at the History Center or another requested location that give everyone the chance to share their stories. Each is themed and use the collection and archives to spark reminiscences. A recent Thanksgiving-themed café had residents at Jill's House Special Care Facility speaking of their favorite food or dish to make for the holiday while making two-ingredient pumpkin cookies.

Memory walks are guided tours that engage the senses in the permanent and rotating museum galleries. Together, participants and the facilitator share stories that are inspired by five to eight objects on display with complementary sensory cues. A Hoosier cabinet paired with the smell of cloves sparks a conversation about holiday traditions and honey baked ham. Standing in front of an exhibit about the Radio Corporation of America (RCA), the theme to the *Andy Griffith Show* gets participants talking about sitting around the television with the family and which child was responsible for operating the volume controls.



Figure 2: Andrea Hadsell (far center), Education Manager, leads a guided memory walk through the permanent exhibit galleries of the Monroe County History Center.

New participants, not knowing what to expect, often begin the memory walk without interjecting into the conversation but grow to laugh and share with the rest of the visitors. One experience to note was a couple who remained quiet throughout the tour but began dancing in the gallery to Chubby Checker's "The Twist" when the facilitator chose to highlight a display of RCA radios. As an effort to continue the dementia-friendly initiative in the museum, a printed version of the memory walk acts as a map of the galleries. Now every Monroe County History Center visitor can start a conversation and share their stories with members of every generation.

Over the last year, the Monroe County History Center has adapted the Living with History programming initiative according to participation and community needs. More memory boxes are in development to encourage reminiscences of the Indiana University experience and parenthood. The guided memory walks have increased from bi-monthly to monthly with plans to train tour assistants amongst the museum's volunteer corps. As the memory lane cafes

develop, these programs have changed from a bi-monthly onsite program to a requested offsite program for the local care facilities. New partnerships are developing with local care partner businesses to increase awareness of the programming initiative for the future.

In addition to the internal changes the Monroe County History Center made during the first year of this special programming, the staff and volunteers are involved in the expansion of the dementia-friendly community. Using additional training from the Alzheimer's Resource Service, staff can provide the dementia-friendly business training to other organizations in the community and the remaining ten counties in the south-central region of Indiana. Specializing in training museums and nonprofits, the Monroe County History Center is assisting in training the second dementia-friendly museum in Bloomington and consulting on the planning of the next Dementia-Friendly Bloomington conference. With this extra training and consultation, the Monroe County History Center acts as a leading resource for implementing new memory programming for dementia-friendly communities developing across the state.

Making the Change

In a community with an existing support system of organizations, the Monroe County History Center made enhancements to its existing programs and exhibits to address the needs of the underserved population of those living with dementia and their care partners. Inspired by existing programs in Canada and the United Kingdom, the Living with History programming initiative utilizes digital collections and exhibit space to better accommodate community members suffering from the disease. These special programs, such as memory boxes and memory walks, engage participants in sharing stories and reminiscences in a safe space. Like the Monroe County History Center, museums can take steps to change their diversity, equity, inclusion, and accessibility strategy to include the aging population.

Museums and cultural organizations of any size can make an effort to become dementiafriendly. Whether it is connecting with a department in the local health care facility, like the Alzheimer's Resource Service, or completing training through Dementia Friends USA, gaining an understanding of dementia as a disease and approaching the community members through positive action is imperative. Online training through organizations like these are easily accessible and are a strong first step to accommodate the needs of the aging population.

Enhancements to existing spaces and programs can be incorporated during routine updates. A small, volunteer-run museum can take similar steps as a large, two-hundred-fifty employee museum in updating wayfinding materials. Museums with tours as a part of their education or interpretation departments can create complementary sensory elements to add to a tour at a low expense. A memory program can highlight objects in a collection or archive that are not often viewed by the public. Creative programming for those living with dementia can be designed for the different stages of disease progression, but at its simplest, it is providing community members a safe space to gather and share their stories.

Aging communities and the increasing number of care facilities mean that museums are not on their own in creating memory programs or becoming dementia-friendly. By establishing new partnerships with professional care partners, local advocates, city or county commissions, and health care professionals, a new network is created to spread the word amongst participants and collaborators alike. Together, a community can create new opportunities in museums and cultural organizations for those living with dementia to live well with dementia.

Acknowledgments

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Notes

¹ Alzheimer's Association, "2019 Alzheimer's Disease Facts and Figures", *Alzheimer's Dement* 15/3 (2019): 17.

² Ibid., 7.

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⁵ Meilan Solly, "British Doctors May Soon Prescribe Art, Music, Dance, Singing Lessons," Smithsonian Institution, November 8, 2018, accessed January 17, 2020.

⁶ Meilan Solly, "Canadian Doctors Will Soon Be Able to Prescribe Museum Visits as Treatment," Smithsonian Institution, October 22, 2018, accessed January 17, 2020.

⁷ Francesca Rosenberg, Amir Parsa, Laurel Humble, and Carrie McGee, *Meet Me: Making Art Accessible to People with Dementia* (New York: Museum of Modern Art, 2009), 9.

⁸ Sam Vaux, "National Museums Liverpool Takes House of Memories to Singapore," House of Memories, National Museums Liverpool, May 2, 2019, accessed January 17, 2020.

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