Chapter Five

MUSEUM CONSTELLATIONS: HOW DEMENTIA-FRIENDLY PROGRAMS BUILD AND STRENGTHEN RELATIONSHIPS

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LIKE CONSTELLATIONS, MUSEUM experiences consist of multiple individual elements that connect into something larger than their unique parts. While the design of each museum constellation varies widely, its components likely include one or more works of art, museum visitors and an assortment of museum staff. The museum experience provides the invisible, but crucial, connection among the various components. Guided tours for people with dementia are special constellations whose purposeful creation reaches beyond the joys of looking at and talking about works of art to the intangible connection of *relationship*.

Creating a Space for Inclusion

Museums often identify as existing for the broader community. Institutions celebrate the multitude of ways visitors may experience their spaces and the range of audiences attracted to their exhibitions and programs. Increasingly, museums are establishing programs to engage visitors experiencing memory loss, as well as their care partners. By offering this type of engagement, museums create opportunities for social interactions at a time when individuals may feel increasingly isolated and disconnected from others. For individuals experiencing memory loss, a dementia diagnosis adds extreme complexity to a person's life in the form of medical appointments, medications, and often-overwhelming worry. Alongside the loss of memories, dementia can limit, or end, favourite social and cultural experiences. In part, this limiting can be due to shifts in cognition. However, perhaps the larger factor in isolation is the social stigma that can come with a dementia diagnosis. Museum visits counter-balance this shift by establishing normalizing experiences and a safe community. Additionally, participants may renew past interests or explore a new environment.

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The Museum of Modern Art (MoMA) in New York City established the "Meet Me at MoMA" program for visitors with Alzheimer's Disease in 2006.[31] Delighted by the success of their tours, MoMA staff presented at museum conferences and published broadly about their work in the years after. The Nasher Museum of Art at Duke University began offering tours for visitors with dementia, "Reflections" tours, in 2013. Originally modelled after "Meet Me at MoMA," tours are conversation-based and groups remain small with a maximum of twelve to fourteen visitors. Tours last ninety minutes, and typically include an hour in the galleries and thirty minutes of either a live musical performance or an art-making exercise. Most importantly, Education staff intends for the "Reflections" tours to serve equally the visitors with dementia and the care partners. Both cohorts of participants are primary to the experience and the tours are constructed to engage each individual through shared conversations about art. Discussions that start with the works of art can grow into deeper considerations of life and meaning. In engaging in these discussions, the participants also build their connections to one another, creating new bonds and strengthening significant relationships. The growing isolation and loneliness of dementia is dangerous and common. People with memory loss withdraw from social interactions for a variety of reasons and that withdrawal accelerates the symptoms of dementia; ultimately, isolation is "associated with reduced survival."[32] By contrast, the community created and fostered by museum-based engagement supports and strengthens social connections and reduces isolation.

Art is a powerful tool for people with dementia because the object of the discussion is directly in front of the viewer. There is no need for abstract thought, although it may occur. A successful conversation does not require past knowledge, or recollection of memories. There is no struggle to recall, no expectation or pressure to remember past teachings and learnings. Instead, the viewers simply relate to the art they see. The emphasis is on the present experience. Based on the needs of the group, conversations can focus primarily—or exclusively—on the visual elements of the artwork, rather than on cultural and historical references.

Admittedly, this discussion format is possible with any museum tour, which raises the question of why people with dementia should not simply participate in general adult tours. Absolutely, all staff giving public tours should welcome all visitors and be trained to create welcoming spaces for all types of participation. However, having tours designed for visitors with memory loss is key because it creates an explicit space for those who feel uncomfortable joining general programs. An Australian survey investigating the barriers to socialization after a dementia diagnosis found that 57 percent of people with memory loss had a fear of being lost in public spaces and 48 percent of

31 Francesca Rosenberg, "The MoMA Alzheimer's Project: Programming and Resources for Making Art Accessible to People with Alzheimer's Disease and Their Caregivers," *Arts & Health* 1, no. 1 (2009): 93–97.

32 Martin Orrell, Rob Butler, and Paul Bebbington, "Social Factors and the Outcome of Dementia," *International Journal of Geriatric Psychiatry* 15, no 6 (2000): 515–20.

individuals said they had difficulty communicating with staff in public settings.[33] When museums establish programs specifically for visitors with memory loss, attendees can participate comfortably because they trust in a welcoming space knowing that others in the group are aware of their condition and that all participants are at ease with it. Explicitly inviting guests with dementia into a museum space is especially important for first-time or infrequent museum visitors who might be surprised by the institution's ability to predict and understand their needs as an audience. The importance of a well-prepared and engaging staff was made clear by feedback from a tour participant who shared, "The warmth and smiles of the [guides] does not go unnoticed or unappreciated. It is wonderful to come up the steps and through the doors to be greeted by friends." Another guest commented, "Perhaps the greatest impact of that one hour was the warmth and kindness Bill sensed from our guide." Relationships matter and extending a radical welcome to museum visitors with dementia can establish a mutually loving community that is not fostered by simple inclusion in a standard public tour.

Enhancing Quality of Life for Visitors with Dementia and their Care Partners

> "The [art] and music were wonderful, but even better was the chance to be out with others who are in the same, or similar, situation as we are."[34]

Tours that are developed intentionally for guests with memory loss also create a comfortable space because everybody participating experiences similar symptoms. In the Australian survey, 25 percent of individuals with dementia expressed a belief that other people seem uneasy as a result of their diagnosis.[35] Yet, when everybody on the tour lives with dementia, any forgotten vocabulary, extended pauses, or repetition of thoughts happen in a safe space. Tours are free of judgement or shame. Instead, the experiences are unrushed and full of encouragement. This atmosphere allows the care partners to be more at ease, which is felt by the visitors with memory loss as the calm of the care partners relaxes them and gives them a sense of security.

In her 2016 research review, Christina Smiraglia found over twenty studies that indicated "the two most common outcomes of [museum-based dementia] programs were increased socialization and improved mood."[36] Feedback from guests at the Nasher Museum aligns with this research. Bill, a museum visitor with dementia, said, "Everybody's got all these problems and today we were laughing and having a good time and we will come back next week remembering about today." It is important to recognize that these outcomes benefit the care partner as well as the person with dementia.

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33 Alzheimer's Australia "Living with Dementia in the Community: Challenges & Opportunities," 2014, https://www.dementia.org.au/sites/default/files/DementiaFriendlySurvey_Final_web.pdf.

34 Direct quotation from Nasher Museum visitor with dementia.

35 Alzheimer's Australia, "Living with Dementia in the Community: Challenges & Opportunities."

36 Christina Smiraglia, "Targeted Museum Programs for Older Adults: A Research and Program Review," *Curator: The Museum Journal* 59, no. 1 (January 2016): 39–54.

Figure 5.1. Tour participants in conversation during a "Reflections" program. Courtesy of the Nasher Museum of Art at Duke University.

Priscilla, who brings her husband Jay on museum tours, said in 2017, "I am deeply grateful for all you do. [The] group is so comfortable, and friendly. It makes such a difference when I don't have to be on my guard when Jay loses his filter, and I lose my cool." For all program participants, socialization and improved moods are the very real intangibles in the constellation of museum-based programs.

Although memory is not required for these experiences to be successful, recollections can still emerge as individuals with dementia consider and discuss the artwork. Edwin was a regular visitor on "Reflections" tours for years. He visited the museum with his daughter Lee. Edwin's quick smile and easy demeanour suggested that he enjoyed the tours, but he seemed more interested in the opportunity to be with others than the artwork. Edwin would respond to questions posed directly to him about the works of art, but rarely contributed spontaneously in the galleries. Instead, he was most vocal during the less structured parts of the day—as the group gathered before the tour started, or over lunch. In those moments, Edwin's conversations rarely included memories. His sociable nature was not lost, but his memory was at a point where he could discuss only the current moment—the weather, the meal he was eating, or other topics directly in front of him.

Then, on a tour, Edwin's group stopped at a seascape in the museum's permanent collection. This work depicts a raging sea with large waves crashing against a jagged, rocky shoreline. Atop one of the waves is a small boat. As the visitors discussed this work,

Edwin surprised the group with a detailed description of what the people on the boat would be facing in the scene depicted. He outlined the ship's best chances of surviving the storm and, when asked by others how he knew so much about boating, Edwin began to talk about his youth growing up in a shore town, as well as subsequent years spent as a sailor in the Navy. The detail with which he spoke was unusual for Edwin and his daughter was visibly delighted at the opportunity to hear her father talk about his formative experiences and share expert information with the group. Engaging with works of art in a facilitated museum experience can create occasions for an individual with dementia to access memories they might not recall otherwise. This moment provided Edwin the opportunity to relive formative life experiences, it provided his daughter a closer connection with her father, and it gave the group new insight into Edwin. Edwin gave meaning to the artwork, but greater meaning arose from the moment shared together.

In the shared museum experience, these moments of recollection are key to both the person with dementia and to their care partner (Fig. 5.1). The person with dementia feels a renewed sense of connection and worth due to the opportunity to communicate a part of themselves. Often, their care partner will express surprise and delight at this brief connection with a loved one. Family members express pleasure at watching a person who is quiet and withdrawn at home become talkative in the galleries. One wife said about her husband, "He's never been much of a talker, so I judge the success of any experience by how much he wants to talk about it. After a 'Reflections' tour, he always wants to talk about what we did and saw." For the partner managing the stress of being a primary care provider for an individual who gradually resembles a former self less and less, these moments offer powerful reminders of someone's personality and, even, humanity.

In the same way that museum experiences can reconnect a friend or family member with a person with dementia, the time spent together on a tour can establish, or strengthen, the relationship between a professional care provider and the individual with memory loss.[37] Residential care staff or in-home care providers who accompany individuals on a "Reflections" tour are equal participants in the experience. Connecting over a work of art can form new bonds in this critical relationship. As with family care partners, conversations on museum tours can provide professional care partners with more information about an individual and serve as a reminder of their personhood.

These moments are spontaneous and museum staff cannot always plan stops that will guarantee recollections. Yet, when this happens, the opportunity to share validates the person with dementia and deeply encourages the care partner.

Beyond observations during the tours, care partners frequently share that a family member will continue to discuss the artwork after their visit, sometimes for days. This indicates that, even with their dementia, short-term memories form and are retained temporarily. Bill, a regular visitor to the Nasher, demonstrated this frequently and would spontaneously ask his wife Gail, "Is today a Nasher day?" Jack, husband and care partner

37 Teri Howson-Griffiths and Gill Windle, "Arts and science combine for dementia care," *Arts Professional*, last revised June 15, 2017, https://www.artsprofessional.co.uk/magazine/article/arts-and-science-combine-dementia-care.

to Patsy, likewise noticed her ability to recall museum visits. He shared, "I usually make decisions about where we go, food to eat and other things, but every time I ask Patsy if she would like to go to the Nasher, she emphatically says yes." This repeated wish to tour the galleries suggests both the pleasure Bill and Patsy took from the museum visits and that they recall the experiences, even at a time when their capacity to remember overall was deteriorating steadily.

Not all tour participants will remember their time spent at the museum. However, without recollection of the museum tour, visitors with dementia still report experiencing residual emotions—feelings experienced beyond their initial cause—after a museum visit.[38] A 2014 study of this occurrence affirms that "findings indicate that patients with Alzheimer's Disease (AD) can experience prolonged states of emotion that persist well beyond the patients' memory for the events that originally caused the emotion. The preserved emotional life evident in patients with AD has important implications for their … care, and highlights the need for caretakers to foster positive emotional experiences."[39]

Thoughtfully constructed museum programs can create experiences that result in prolonged positive emotional responses, regardless of an individual's ability to remember.

Deepening Connections through Art-Making and Music

In addition to the time spent in the galleries, many tours for people with dementia—including those at the Nasher Museum—incorporate art-making. At the Nasher, visitors may explore a single technique such as screen-printing or watercolour, or they may enjoy a single medium such as clay. Local artists may join the tour to lead the hands-on component and share their own expertise. These opportunities enable participants to express themselves visually and can be playful and exploratory. Too often, after a dementia diagnosis, individuals may stop exploring new experiences and interests. Art-making on the tours pushes against that tendency to withdraw from experimenting with the unfamiliar. After an art-making tour that focused on photography and encouraged participants to take their own pictures, a visitor shared about her husband, "He hasn't wanted to make a decision about anything—not even what he wants to eat—for a long time. But, when we had the Polaroid cameras, I asked him if there was something he wanted to photograph and he knew right away what and where he wanted to take a photo. I was thrilled!"

It can seem counter-intuitive to describe individuals with memory loss as learning new skills, and yet we see it happening at the museum when art making prompts a visitor with dementia to uncover new interests.[40] Laura recognized her husband Harold's joy making art on tours and—outside of the museum—enrolled him in watercolour

38 Carolyn Halpin-Healy, "Well-Chosen Objects Support Well-Being for People with Dementia and Their Care Partners," *Journal of Museum Education* 42, no. 3 (July 2017): 224–35.

39 Edmarie Guzman-Velez, Justin S. Feinstein, and Daniel Tranel, "Feelings Without Memory in Alzheimer Disease," *Cognitive and Behavioral Neurology* 27, no. 3 (September 2014): 117–29.

40 Jeremy Kimmel and Paul M. Camic, "More Than Reminiscence: Museum Object Handling, Dementia and New Learning," (lecture, Museums Association Conference, November 6, 2015).

Figure 5.2. Reflections tour incorporating music.
Courtesy of the Nasher Museum of Art at Duke University.

classes. Harold was a life-long bird enthusiast and he combined his love for birds with his new pursuit of painting. After Harold developed this new skill and produced a body of work, a local library exhibited his bird paintings and celebrated Harold at an opening reception. Beyond Harold's own enjoyment and growth, his new painting skills taught those around him—his wife, museum and library staff, and visitors to his exhibition—about the ability of people with dementia to continue learning and evolving.

The art-making may also provide the care partners with a better understanding of how a participant's skill set has changed. Sometimes a family member or friend may find that the abilities of their loved one have declined beyond what they realized. It can be disheartening to find that an individual has lost a skill such as the use of scissors or how to hold a paintbrush correctly, and yet it is important information for the care partner. A benefit of the shared museum experiences is that the museum staff and visiting artists can assist in identifying new ways for a participant to communicate; perhaps the individual rips the paper or paints with their hands. After an art-making tour, one attendee contacted the museum to say "Thank you again for this wonderfully kind service you provide with sensitivity to both the capabilities and limitations of this special target audience." The care partner feels supported and not alone, even as new challenges are identified. Like art, music can connect people with dementia to their deepest memories. Scientific research reports the use of music as an effective tool for working with those with memory loss.[41] At the Nasher Museum, music is part of many of the "Reflections" tours (see Fig. 5.2). Musical artists perform in the galleries and connect their songs

41 Nicholas R. Simmons-Stern, Andrew E. Budson, and Brandon A. Ally, "Music as a Memory Enhancer in Patients with Alzheimer's Disease," *Neuropsychologia* 48, no. 10 (2010): 3164–67.

directly to the theme of the tour, as well as to the visual art on display. They engage the visitors in conversation about both the music and how it relates to the surrounding art. Frequently visitors will physically react to the music, either through movement or by joining the musicians and playing alongside them. After one tour that included music, a guest shared, "[The] integration of music and art was a win. So much so that my husband initiated conversation about what we heard and talked about it to our daughter [whom] we saw when we left the museum." The music connected him to the art and he was able to share a moment in the present with his daughter due to the experience.

The story of Charles powerfully conveys the profound impact of music. Charles participated in a tour during a Joan Miro exhibition at the museum. From the Catalan region of Spain, Miró (1893–1983) was an artist known for combining elements of surrealism and abstraction in his paintings and sculptures. To complement the tour of work by a Spanish artist, the visit included a performance by a Spanish guitarist. When the group was first introduced to the musician, Charles shared that he played drums as a young man. The musician had a drum with him and invited Charles to play. Charles accompanied the guitarist and his performance deeply moved many group members, including Charles's wife. After the tour and music finished, she disclosed that she had known nothing about his earlier life as a musician; this was a second marriage for Charles and his wife, and his drum playing was something he had not yet shared. In the days after their tour experience, she learned from family members that Charles and his cousins performed together in a band as young adults. At a time when she felt that she was losing touch with her husband, Charles's wife learned something new and surprising about his past. As with the artwork, music unexpectedly allows visitors to reveal more of themselves to those who love them most. At all levels of cognition, art, music and humanity together produce experiences that surpass the impact of the individual components.

A shared lunch in the café extends this feeling of community and allows care partners an additional opportunity to connect and support one another. This lunch is a valuable piece of the museum experience as it solidifies community. Unstructured time spent over a meal strengthens the invisible connections the museum experience seeks to establish.

Programs for People with Dementia as a Catalyst for Empathy Building

Beyond the positive impact on the tour participants themselves, "Reflections" tours profoundly impact museum staff and university students (Fig. 5.3). The staff facilitating the tours consists of community members and Duke University undergraduate, graduate, and medical students. Tour guides report a greater appreciation for the abilities of individuals with dementia, while discussions of art allow staff and students to grow beyond their preconceptions of older adults. Increased empathy and better understanding of people with cognitive differences are not limited to the educators guiding the tours. Broadly speaking, a measurable decrease in prejudice towards people with cognitive loss can be observed among museum staff at institutions that offer these programs.[42]

42 Carolyn Halpin-Healy, "Report from the Field: Multi-Cultural Dialogue and Transformative

Figure 5.3. The author with a tour participant during a "Reflections" program. Courtesy of the Nasher Museum of Art at Duke University.

Ultimately, the positive ripple effects of the tours extend well beyond the tours themselves.

A growing body of research outlines the benefits of museum-based experiences to medical students specifically. A 2015 study declares, "Such activities may positively influence students' formation as compassionate, clinically adept physicians able to care for persons whose diagnoses, dispositions, and dire prognoses may be difficult to bear."[43] For medical students as well as other undergraduate and graduate student staff members, this experience of working with people with dementia affects their perspectives as they prepare for careers in research, museums, and medicine. These students will step into their chosen professions better understanding the individual with dementia as a whole person. For communities, it means that more community members across a wide variety of professions will possess a more empathetic understanding of people with memory loss, and, hopefully, cognitive differences more broadly.

It is equally important that university students who participate in museum-based programs for people living with dementia will take with them the expectation of museums as spaces that engage the full community. As emerging professionals, and as the next wave of museum consumers and supporters, students involved in these tours recognize the power of the arts and museum-based experiences. They can advocate for these programs to be broadly available in communities that have not already embraced arts programming as an important intervention.

As our population ages, diagnoses of dementia grow exponentially. While medical researchers work to find a cure, neuroscientists work to understand the cognitive function of the brain when viewing art to understand neurological responses to arts-

Learning in *Arts & Minds* Programs at The Studio Museum in Harlem," *Museum and Society* 13, no. 2 (2015): 172–87.

43 Marcia D. Childress and Donna Chen, "Art and Alzheimer Dementia: A Museum Experience for Patients May Benefit Medical Students," *Neurology* 85, no. 8 (August 2015): 663–64.

based interventions more fully. There is growing support for neuroscience research to take place in non-laboratory spaces, such as classrooms, museums, and libraries, as the emergence of mobile brain/body imaging (MoBI) technology allows scientific research to extend beyond traditional laboratory walls. Museums provide real life settings in which scientists can observe brain activity when individuals connect with works of art, museum staff, and other visitors. Various teams have used MoBI technology to consider the experience of general museum audiences, but the research has not yet looked specifically at visitors with dementia. The freedom allowed by mobile technology creates exciting opportunities for neuroscience and museum educators to collaborate on interdisciplinary research to begin to understand how the brain of an individual with dementia responds to museum-based engagements. Ultimately, the development of neuroscience research in museums may help museum professionals to explain more fully the positive impacts routinely observed in tour participants. This work may also support the empathetic aspect of these programs as interventions can be tailored more specifically to the experience of visitors with dementia based on what is learned from research efforts.

As doctors and neuroscientists work towards solutions for families living with dementia, it is the responsibility of our communities and our cultural institutions to do the same. When museums prioritize this audience and offer opportunities for appropriate engagement and participation, the institutions make a public statement about the societal value of older adults and individuals with cognitive differences. For people with dementia in a museum-based program, the combined elements of intellectual engagement, group socialization, and comprehending compassion generate a constellation effect in which individuals can shine brightly and to their fullest.

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