

# Arts in Mind: A Multidisciplinary Approach to Museum Programs for Persons Living with Young-Onset and Early-Stage Alzheimer's Disease

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## ABSTRACT

This paper reflects on Arts in Mind, an ongoing museum-based program for those with Young-onset Alzheimer's or in the early stages of memory loss. Co-developed in 2019 by the authors, an art therapist with experience in Alzheimer's clinical trials research and two museum educators. Arts in Mind is a monthly program that invites people living with Young-onset Alzheimer's and their care partners to look at and make art together. Arts in Mind responds to a previously unmet need for programming specifically designed for the Young-onset Alzheimer's population and individuals in early stages of the disease. Sessions are anchored in the art encounter, accessible, responsive, and experiential. Additionally, the program a site of mentorship for the next generation of art therapists, museum educators and medical professionals. This paper offers a replicable and sustainable partnership model for museum and art therapy-based memory loss programs for an often overlooked population.

## KEY WORDS

Museum education, Alzheimer's Disease, Art Therapy, Young-onset, Memory Loss, Social Prescription

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In this paper, we—an art therapist with experience in Alzheimer’s disease clinical research trials and two museum educators—reflect on our experiences designing and facilitating Arts in Mind, a co-created, accessible, and engaging museum program for people living with Young-onset and early-stage Alzheimer’s and their care partners. Arts in Mind at the Yale University Art Gallery provides participants and their care partners the opportunity to embark on art experiences that combine close looking, conversation, and artmaking. The program began when Angel Duncan approached Jessica Sack and Rachel Thompson at the Yale University Art Gallery in 2019. Knowing that the Yale University Art Gallery already had a program for those with moderate-stage memory loss, Duncan proposed co-developing a program for those with Young-onset Alzheimer’s and those in the early stages of Alzheimer’s. Her work in clinical research showed her firsthand that Alzheimer’s research centers often serve as one of the only social outlets for this population.

While clinical trials aim to find a cure by slowing and stopping the disease’s progression, the arts aim to preserve quality of life. Current research studies expand upon our understanding of how the arts impact the brain and may even offer clues into consciousness and where memory pockets, areas of the brain where memories are stored, may be housed (Badhwar, 2018). As awareness of and interest in using dignified arts programs grows, expressive art therapy is becoming an increasingly popular and promising means of enhancing quality of life for the Young-onset Alzheimer’s population as a complement to research trials (Flatt et al., 2015). Additionally, art museum programming for visitors with memory loss has become more common as a way to normalize the inclusion of those living with dementia in society. We recognized the potential in bridging the fields of art therapy and museum education to design an experience that combined art appreciation with artmaking, particularly for those with Young-onset Alzheimer’s, whose unique needs are often overlooked.

### **Background: Responding to an Unmet Need**

A gradual growth in Alzheimer’s awareness has been marked by an emergent emphasis on destigmatizing the disease and improving quality of life in the absence of a cure. In some cases, medical professionals are seeing community programs as potentially therapeutic and have begun to recommend “social prescriptions,” non-medical interventions often provided by local community groups that aim to supplement medical treatment by providing activities for wellbeing, enjoyment, and social engagement (Drinkwater et al., 2019). Chatterjee and Thomson (2015) have applied the concept of social prescribing to describe how physicians might recommend informal treatment for patients with Alzheimer’s in public spaces as opportunities for community engagement, social interaction, and recreation (p. 306).

In recent years, the arts and humanities, by way of art therapists and museum educators, have expanded offerings for those living with Alzheimer’s, particularly for those in the moderate stage of the disease as a way of normalizing memory loss in public spaces. The Médecins francophones du Canada, a physicians membership group, partnered with the Montreal Museum of Fine Arts in an effort to better serve patients with physical and mental health ailments (BBC News, 2016). The initial phase of their partnership was to provide up to 50 social prescriptions for a visit to the Montreal Museum of Fine Arts. The concept that “art is good medicine” has encouraged patients to sign up to attend the museum’s exhibits. Following this project, the United Kingdom initiated a campaign to implement museum visits

as prescribed interventions throughout the U.K. by 2023 (Solly, 2018). Physicians are showing interest in observing how being in the museum and viewing art enables their patients to find peace of mind, ease suffering, and combat symptoms of isolation and loneliness.

Museum programs have become recognized as sites of informal care for people with Alzheimer's, but those with Young-onset Alzheimer's are often overlooked in the design of these programs. While Alzheimer's is often seen as an "old person's disease," Young-onset Alzheimer's is a rare form of the disease affecting persons younger than the age of 65. Young-onset Alzheimer's impacts approximately 200,000 to 240,000 people in the United States (Mayo Clinic, 2020). However, as healthcare professionals may dismiss younger individuals seeking diagnosis as being too young to have memory loss, and as physicians do not always know where to turn for help in assessing these younger patients' symptoms, these numbers are presumed to be underreported (Alzheimer's Association, 2019).

Both individuals with Young-onset Alzheimer's and those over the age of 65 years who are in the early stages of Alzheimer's disease often find themselves feeling trapped. They feel too cognitively intact to attend a day-stay or need homecare services, yet they experience anxiety and embarrassment from their inability to keep up with conversations, and therefore forgo their usual social activities (Riley et al., 2014). Most arts-based programs have been designed for those in the moderate to later stages of the disease, and therefore, those with Young-onset Alzheimer's and those in early stages of Alzheimer's disease have had fewer opportunities to participate. Persons living with Young-onset and early-stage Alzheimer's who lack social opportunities may be particularly vulnerable to loneliness and isolation, factors that can potentially exacerbate the disease's progression. Additionally, there is an increased risk for developing a neurological disorder, such as Alzheimer's disease, when mental and psychosocial stressors fail to provide social opportunities (Sutin et al., 2020; Hsiao et al., 2018). In developing Arts in Mind, we saw a need for engagement for this subset of the population.

We recognized that museum programs could be particularly beneficial for people living with Young-onset Alzheimer's disease because they have elements that are both public and intimate; participants visiting museums as part of memory loss tours are able to maintain an important connection to public life with their care partners while still feeling safe among their group of peers in an experience designed specifically for them (Brorsson et al., 2011). This public, yet protected, environment allows for a sense of intimacy, both among the group and between participant and care partner, while maintaining an environment of excitement, spontaneity, and connection that comes with a social outing. Additionally, because museum programs attract a variety of audiences with a broad range of needs and goals, museum educators are trained in using pedagogies that are structurally flexible and readily adaptable to the particularities of the groups they serve. For Young-onset populations, a session's structure and content can be adjusted to the varying needs of each individual in the group as well as the often rapid progression of the disease. Museum educators' methods for facilitating art appreciation experiences can be deepened by the expertise of art therapists, who can provide opportunities for deeper psychological perspectives through the artmaking process. This commitment to collaboration has been a guiding principle in the development of Arts in Mind.

### **Designing Arts in Mind: A Multidisciplinary Collaboration Connecting Medical Professionals, Art Therapists, Museum Educators, and Their Students**

In designing Arts in Mind, we drew on and learned from each other's unique expertise working with those with Alzheimer's in our own professional settings: art therapy, clinical trials research, and museum education. Recent research has suggested that when professionals with different areas of expertise collaborate to design, implement, and evaluate art museum programs for people with Alzheimer's disease, art museums can be effective settings for social prescriptions. Flatt et al. (2015) hypothesized that, in the context of a program for people with Alzheimer's, a key element of the program's success was the "early and sustained collaborations between the University of Pittsburgh and the [Alzheimer's Disease Research Center's] Education and Information Core and the Andy Warhol Museum" (p. 388). The medical perspective has been integral to Arts in Mind since the program's design and inception, as staff from the Yale University Alzheimer's Disease Research Unit (ADRU) helped to identify the participants from their research center who might benefit from a museum program as a social prescription. Their medical expertise and knowledge about study participants' interests allowed them to recommend participants to Arts in Mind. They also recognized the need for more opportunities for this population to participate in arts-based programming. Once our team had identified the group of participants based on referrals from the ADRU, we collaboratively planned sessions to match their interests, needs, and preferences.

Additionally, to ensure programming like Arts in Mind becomes part of the practice for the next generation of art therapists, museum educators, and medical professionals, we made sure to incorporate mentorship opportunities for emerging professionals in each discipline. Since the creation of Arts in Mind, medical school residents, art therapy students, and Wurtele Gallery Teachers—Yale University graduate students trained as museum educators—have been participant-observers in Arts in Mind sessions and have contributed to the program's design and evaluation. These mentees have become valuable members of the group and often engage with the participants in conversation about the art.

### **Arts in Mind: The Product of Collaboration**

We designed Arts in Mind to connect the fields of medical research, art therapy, and museum education to create a program that could be used as a social prescription for individuals living with Young-onset and/or early-stage Alzheimer's disease. By combining art therapy modalities with museum spaces and pedagogies, Arts in Mind seeks to provide an enjoyable, social, accessible experience that engages abstract thinking while activating the imagination and encouraging self-expression.

A typical Arts in Mind session includes two to three artworks that span a variety of styles, time periods, and geographies. Each session has a two-part structure that begins with the museum educators guiding the group through closely looking at the chosen works of art by facilitating inquiry and dialogue. Participants—both those with Alzheimer's and their care partners—observe the artworks, describe what they see, and make connections. Second, the art therapist leads an art experiential that connects to the artworks just viewed and discussed. Participants are invited to draw or use gallery-safe materials while engaging in the directive in front of the work of art. After making art together, the art therapist leads a

reflective conversation in which participants along with care partners share with the group what they made and what it means to them. In addition to this two-part structure, each session of the program includes four common elements: sessions are anchored in the art encounter, accessible, responsive, and experiential.



*Figure 1. Gallery Teachers, art therapy students, and resident physicians engage in close looking activities with participants.*

### **Anchored in the Art Encounter**

The art encounter is the core experience of Arts in Mind. Drawing on best practices from both museum education and art therapy, we select objects that have the potential to foster discussion, activate memories, and connect to an art experiential. We select one or more objects that can be grouped by themes, such as landscape, heroes of stories, the decisions artists make, and duality. Choosing a theme serves multiple purposes. For the facilitators, grouping objects based on a theme helps to guide conversation, drawing out and highlighting connections among the artworks. For participants, those in the earlier stages have been able to make connections between objects within a chosen theme and have enjoyed the task of comparing/contrasting works of art within a theme. Participants in the later stages might not be able to recognize and make connections among artworks within a theme, but still find meaning in each artwork, one at a time. Additionally, care partners enjoy the thematic framework of the sessions.

While the art encounter is the anchor for all participants, we have found that the nature of this encounter differs depending on the stage and severity of Alzheimer's for each individual. For those in the earlier stages, the conversation has focused on motifs, techniques, and aspects of the artwork such as color, material, and mood. For those in the later stages, the art encounter serves as a springboard for other types of discussion, such as memory sharing and storytelling, and for the art experiential. One Arts in Mind session included discussion of a photograph of Yosemite National Park, along with an oil painting depicting the landscape from a similar vantage point. Guided by our open-ended questions, participants in the earlier stages as well as some care partners compared and contrasted the two images, pointing out areas where the painter might have deviated from the reality that the photograph showed. However, those in the later stages were more interested in responding to the personal questions we asked, such as, "Has anyone been to a place like this?" or "Which do you prefer—the painting or the photograph?" We found that participants—even ones who were usually quiet—were eager to share their memories that the artworks provoked as well as their preference between the two pieces.

### **Accessible**

When planning Arts in Mind sessions, we consider a variety of logistical factors to ensure that the museum is accessible for participants, keeping in mind that, for people living with Alzheimer's, accessibility is a "constantly changing experience" (Brorsson et al. 2011, p. 591). Accessibility encompasses a variety of factors including not only the ease of physical access, but also elements such as noise levels and crowding. We take these factors into account when designing Arts in Mind visits to ensure that spaces are not sonically or spatially overwhelming. We choose galleries that were not being used by any other groups and that are large enough to accommodate a group of approximately 20 participants, including care partners, leaving enough space for comfortable movement during art experientials. We aim to make travel throughout the museum as direct as possible, avoiding especially long or unnecessary travel between objects whenever possible to allow the group to remain focused and aware.

We also consider visibility in our choice of artworks, taking care to select objects that are both large enough to be visible even from a distance, and avoiding artworks that are difficult to see because of low contrast, dark colors, or the presence of a glare.

Additionally, we design the structure and content of sessions to be accessible for Arts in Mind's target population. We have found inquiry-based pedagogies, such as Visual Thinking Strategies (Yenawine, 2013), as well as thinking routines, such as "See, Think, Wonder," (Project Zero, 2019) to be adaptable for the Arts in Mind model, and in implementing these strategies, we take care to adopt a conversational tone rather than a quizzing one. Instead of asking a long series of closed-ended questions that prompt participants to identify elements of the artwork, we might opt to ask fewer questions—ones that are open-ended in nature—to generate discussion about the piece. When looking at a landscape painting together, we might ask, "What are you noticing?" or "What does this make you think about?" rather than questions that may have only one right answer.



*Figure 2. The museum has foldable stools on rolling carts that are wheeled to each object so that participants can walk without carrying them.*

### **Responsive**

Arts in Mind sessions are carefully planned with structure and sequence but are responsive enough to meet the needs of the group. Alzheimer's disease progresses more rapidly for some than others, and Young-onset in particular is sometimes thought to progress more rapidly than other types of Alzheimer's (Stanley et al., 2014). In early sessions of Arts in Mind, we recognized that most of the participants had been recently diagnosed and were in the early stages of Young-onset. This meant that the participants were aware of the effects of memory loss on their own behavior but could still engage in and enjoy abstract thinking and discussion. A flexible teaching plan accommodates a range of needs among the group's participants.

In one session, an adaptation we made was transitioning from abstract to concrete themes and adjusting the questions and artmaking directives to allow for a range of engagement from the participants based on their own needs and abilities. We noticed that participants in the earlier stages of the disease were interested in discussing historical and thematic links between works of art, and as the disease progressed, they became more interested in the visual aspects of single objects. This also played out in the art experientials; those with the earlier stage diagnoses were able to create something in which they predicted what would happen next when an image showed a potential narrative, while those with more advanced Alzheimer's preferred observational drawing from the artworks.

Responsiveness is also vital given that the makeup of the group can vary from month to month due to a variety of factors, such as doctor's appointments or participants having a

bad day. Thus, we often tailor the general plan as needed and adapt in the moment to best accommodate the abilities and preferences of attending participants. This flexibility requires a great deal of what Schon (1983) refers to as “reflection-in-action,” which in our case, entails consciously reflecting on informal feedback we receive from participants and adjusting as necessary (p. 129). In one session, we spent longer than usual on the close looking segment of the program. As we were discussing a landscape painting, we heard one participant remark to his care partner: “If we spend any more time talking, we won’t get to draw!” This signaled to us that participants might be getting restless, and in order to maintain their focus, we transitioned to the art experiential portion of the session.

### **Experiential**

The art directive portion of the program is a key component of sessions, and the art therapist is integral to ensuring that the art directives are meaningful for participants. For those living in the more moderate to later stages of the disease, selected artwork and themes may be more concrete in imagery and discussion points with a step-by-step process of artmaking. Whereas for those living in the Young-onset or early stages of the disease, the artwork selected is aimed to invoke an abstract thinking process where participants can reflect on and discuss the art. Participants are also able to focus their attention on specific details in the artwork, relying on their insights of what they see and in exercising their imagination on what the art is meant to represent. Engaging in art experientials either during or after observing the artwork, participants make art based on the theme of the visit. For example, looking at shapes and textures within an artwork, participants may use cut-out felt shapes and yarn to create their own artwork. Other artmaking directives may include looking at an artwork and focusing on a certain section within it and sketching what they see.



*Figure 3. Participants use felt and yarn kits to create scenes inspired by the artworks on view and to experiment with elements of art, composition, and abstraction.*

The art experiential component of the session also includes a space to reflect on the process of making. The art therapist leads this conversation, inviting participants to respond to questions such as “What was it like to create your artwork?” and “What would you title your piece?” Often, the title that participants give their piece can offer insight into their thinking and state of mind. This is an opportunity for both partners to share their creative process and to make meaning of their work, creating further opportunities for self-expression and connection—both between couples and among all those involved with the group. Often, this reflection conversation has become a space for laughter, encouragement, and even awe at the creativity of the members of our group.

The multidisciplinary nature of Arts in Mind allows for each of our areas of expertise—medical research, art therapy, and museum education—to build on the strengths and deepen the impact of the others. Coupling looking at art with making art allows participants to tap into thoughts and emotions, thereby using expression and artmaking to process the art on a deeper level. Additionally, the experience allows the care partners to see their partner in a different light. Rather than having to serve as their partner’s memory, they are able to enjoy a museum program that is designed with both their needs and their partner’s needs and abilities in mind. An ongoing goal of the program is to provide an environment in which participants can connect and collaborate with each other and be true partners rather than caregiver and diagnosee.

### **Responses of Care Partners and Medical Providers**

Each session of Arts in Mind concludes with built-in time for reflection in order for us to understand participants’ responses to the program and to take requests for themes and topics for future sessions that connect to participants’ interests. Care partners provide additional context to participants’ responses and help facilitators adapt to the group’s needs. Some care partners have shared that participating in Arts in Mind has deeply engaged their significant other. During one session, a care partner shared that when her significant other responded to questions asked of the group, he spoke directly to her and stayed engaged for longer than expected. We later learned that he specifically resonated with the photograph we showed because he was a photographer. Another participant living with Young-onset Alzheimer’s shared his enthusiasm with the group and reflected that he found art to be comforting and mentally stimulating, and that the introduction of art has further enriched his use of time at home. In addition, spouses of those affected with Alzheimer’s have reported that they have been able to reconnect with their loved ones in more meaningful ways, strengthening relational bonds. One spouse commented on the program:

This was the first time that I have seen my husband’s self-confidence come back since his diagnosis. He did not feel confident in speaking in front of people. To see him speak in front of an entire group of people who he didn’t know about the art exhibited, was so thrilling to see his self-confidence come back (personal communication, March 1, 2020).

Another care partner found that communicating through the art experientials was a means for substituting words when her partner struggled to verbally express his needs. She

expressed that the art experientials brought a calmness in the mind, providing easier access to self-expression than what could be done with words. The care partners see Arts in Mind as a space for them as well, giving them a place to connect with others while stepping back from the caregiving role. The repetition of coming together in ongoing dialogue among all parties—facilitators and their mentees as well as participants and their care partners—creates a sense of cohesive community.

We also invite feedback from the medical researchers and professional caregivers who attend Arts in Mind. After one session, the clinical researchers and caregivers who attended the program reported being able to connect with participants on a deeper level that allowed them to see the person beyond the disease. Additionally, two of the resident physicians working as ADRU study raters remarked that, as they were embarking on their careers, this program helped them to see the human side of patients and learn that social prescriptions are an option. Reflections such as these inform the ongoing development and adaptation of the program.

### **Creating and Sustaining Impact through Mentorship**

Both the art therapist and museum educators mentor students being trained in their respective fields, and Arts in Mind has become an opportunity for students to gain hands-on experience. As part of her training, Emily Scranton, a graduate student from the Masters of Art in Art Therapy and Counseling program at Albertus Magnus College, has participated in and co-led art directives in Arts in Mind sessions. She gained an expanded understanding of museum teaching coupled with art therapy techniques that can be applied in her future career with this population. Reflecting on her experience with Arts in Mind, Scranton remarked:

Art can be as grounding for this population as it can be activating. I've witnessed participants sketching with great focus to capture details in artwork. As a facilitator, I've learned to use the artwork as a "home base." It becomes a rallying point for discussion, attention, and deeper connection (personal communication, March 30, 2021).

Our hope is that as graduate students Wurtele Gallery Teachers learn to work with visitors with memory loss during their formal education, such offerings will become part of their own expectations for what museums provide within their regular educational programming. Our goal is that when our student mentees move on to full time employment after graduating, they will apply this flexibility and adaptability to their future work with greater awareness of people's varying needs, continuing to normalize museum art therapy programs as social prescriptions in their respective fields.

### **Building a Replicable Model**

Some neurologists have recognized that the arts can meet their need to treat their patients living with Alzheimer's in more holistic ways. Daniel C. Potts, MD, FAAN, attending neurologist at the Tuscaloosa Veterans Affairs Medical Center and Affiliate Faculty at the University of Alabama-Birmingham and the University of South Alabama Medical Schools, states:

We healthcare providers are not particularly good at breaking bad news. Diagnoses such as Alzheimer's, that have no globally effective treatments or cures, are difficult to make. But we must keep in mind the goal of helping people to live as well as possible with the condition, even if it can't be cured. A diagnosis of Alzheimer's or another kind of dementia does not render one less a person, and therefore less in need of those activities and relationships that enhance quality of life in all of us....Activities and opportunities such as these [Arts in Mind] may well ease the burden of care partnership and help to build more compassionate, inclusive communities, in addition to helping persons with Alzheimer's and other dementias to live as well as possible (personal communication, December 29, 2020).

We hope that as more physicians become aware of the need for social opportunities for their patients with Young-onset Alzheimer's, they will be encouraged to refer patients to programs like Arts in Mind as an effective treatment modality that complements medical care.

The multidisciplinary approach modeled through Arts in Mind shows the potential benefit of medical professionals, art therapists, and museum educators working together to provide care for those living with Alzheimer's. This collaborative method creates an important conversation among medical professionals, art therapists, and museum educators that can serve as a model for holistic and integrated care for our aging communities while ensuring that the next generation of practitioners receives training to sustain these programs. The multi-disciplinary approach that cuts across the existing division between the medical and art fields means that medical professionals, therapists, and museum educators can work together rather than in isolation to create holistic care programs for those struggling with the early stages of memory loss disease. Stronger partnerships between these fields means that recently diagnosed individuals can learn about programs like Arts in Mind through research centers, medical providers, or assisted living communities at a much earlier stage, gaining access to critical social and creative outlets along with their care partners. The model also allows for holistic engagement with care partner and diagnosee, allowing the care partner to step back from the role of caregiver and instead become a partner to the participant during the program. We found that our consideration of the needs of the care partner and their relationship with the participant living with Alzheimer's helped the care partner to find relief from stress and an opportunity to engage with their loved ones in a dignified way. While there is no cure for the disease currently available, we believe that collaboratively-designed arts programs such as Arts in Mind hold great promise for complementing medical treatment and enriching quality of life for those with Young-onset Alzheimer's.

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