

Design for Creative Aging

Cal Dobrzynski

A thesis submitted in partial fulfillment
of the requirements for the degree of

Master of Design

University of Washington
2020

Committee:

Kristine Matthews
Annabelle Gould
Dr. Lee Burnside

Program Authorized to Offer Degree:
School of Art + Art History + Design

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University of Washington

Abstract

Design for Creative Aging:

Can collaborative art-making enhance non-verbal communication between individuals living with dementia and their care partners in nursing homes?

Cal Dobrzynski

Chair of the Supervisory Committee:

Kristine Matthews

School of Art, Division of Design

As we continue to live longer, the number of people diagnosed with Alzheimer's Disease is on an upward trend. Today, 5.8 million Americans are living with Alzheimer's, and according to the National Alzheimer's Association, nearly 14 million individuals will be diagnosed with the disease by 2050 [1]. With the rising cost of both in-home and out-of-home professional care and the increasing desire to age-in-place, caregiving by family members is becoming more commonplace in North American households.

At first, this thesis set out to explore if art-making could cultivate forms of non-verbal communication within domestic settings between individuals living with progressive Alzheimer's and their family caregivers (spouse, daughter etc.). However, due to the spread of COVID-19, this thesis asks a new question: Can art-making enhance non-verbal communication between individuals living with dementia and their care partners in nursing homes? How can caregivers and individuals living with dementia feel empowered to make together? *Design for Creative Aging* explores a series of in-person and virtual art making workshops in a Seattle-based memory unit.

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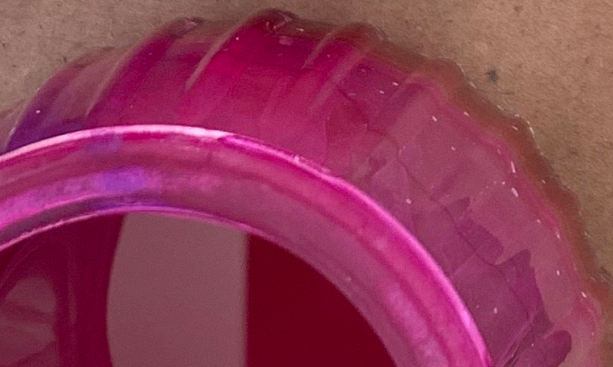
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Design for Creative Aging



Personal Motivation

Doris Barlett lived in central Pennsylvania her entire life. For nearly 60 years she called the purple Victorian-style mother-daughter house on Elm Drive in Watsonstown, Pennsylvania her home. Doris lived on the 'mother' side of the home while her son, Chuck, and his wife Vondelle lived in the 'daughter' side.

The only thing separating the mother from her son was a wall.

So when Doris was diagnosed with Alzheimer's disease in 2001, she continued to live in the home she had known for the majority of her life, a place where she felt safe, comfortable, and most importantly, in control. She could stay in the space where she watched Dancing with the Stars every Monday night, sitting on the same green and white checkered couch with the decorative electric fire flickering in the background. The place where she knew how to use the rotary telephone that hung on the kitchen wall, despite it being 20 years out of date.

As her Alzheimer's symptoms progressed, Doris began to confuse dates and times. She would write notes to herself so that she could try and remember birthdays and appointments, but nothing seemed to work. Chuck would check on her nearly ten times a day, preparing her meals and making sure that she was taking her medicine at the correct times. Check-ins were more prominent on Mondays, when Dancing with the Stars was on, to make sure the television was working properly, as Doris had trouble turning it on and off.

At the time, Watsonstown did not have community facilities for families taking care of a loved one with Alzheimer's disease or any cognitive disability. There were no organizations that offered in-home care to relieve Chuck from his duties. And there were certainly little to no programs available in



Doris and her first husband, Sterling



Doris's home on Elm Drive. It has since been repainted



Cal and Doris during a Christmas Party - late 1990's



Doris and her children John and Caroline and second husband, John - mid 1950's

the small town of 2,250 people. So, the television became Doris's main form of stimulation.

When I turned 12, I started to write letters to Doris, my great grandmother. Chuck, my great uncle, would send back her responses. It quickly became our form of communication—penpals, if you will. When my nana was cleaning out Doris's home on Elm Drive a few years later, she found the letters I had sent to my great-grandmother. The letters were tied up with ribbon in a kitchen drawer. My nana never knew we had been penpals. She said she cried when she read them.

In the winter of 2018, I went back and found the letters that Doris wrote to me, stuffed in a folder in my childhood armoire. While her letters were usually incoherent, her penmanship never faltered and she always drew doodles and drawings in the margins, something I hadn't thought much about when I was 12. But seeing it then made me wonder about creativity that continues to live in people despite having a diagnosis of Alzheimer's disease.

Doris lived in her home until April 30, 2009, thirteen days before she passed away. It was at this point that her children decided to place her in a nursing home facility, but only for rehabilitation. Doris would ask, 'how long am I going to be here?' and Caroline would tell her that she would head back to her Elm Drive home soon, that this was only temporary. But on the thirteenth day in the nursing home facility, Doris passed away.

At her funeral, people were asked to make donations to the American Diabetes Association—my great grandmother didn't have diabetes. Doris had always told my grandmother that she was too embarrassed to have people find out that she had 'issues' with her memory. She was scared that people she knew her entire life would mock her, make fun of her. So there was no mention of her cognitive impairment in her obituary. There was no talk of it at her funeral.

I had just turned 15 when my great grandmother passed away. And while 11 years have passed, her diagnosis and death have had a profound effect on my life and the way I see the world.

When I found the letters Doris and I wrote to each other again, at the age of 24, I started to think about how we, as human beings, no matter our cognitive abilities, have the innate craving to create. Whether it is doodling in the margins of a letter, quilting, or sketching the view out the window, the desire to make can stay with us as we age. I started to think about everything that my great grandmother had lost - her sense of time, her alertness, her ability to take care of herself. But there was something inside of her that remained. When I saw the letters again, the doodling on the papers gave me hope and made me wonder if creativity could unlock the door to non-verbal communication.



Doris and her
youngest son,
Chuck



Doris, Chuck and her 3 grandchildren, Mark, Jack and Sean - mid 1970's



Cal and Doris during Christmas Eve - late 1990's

Introduction

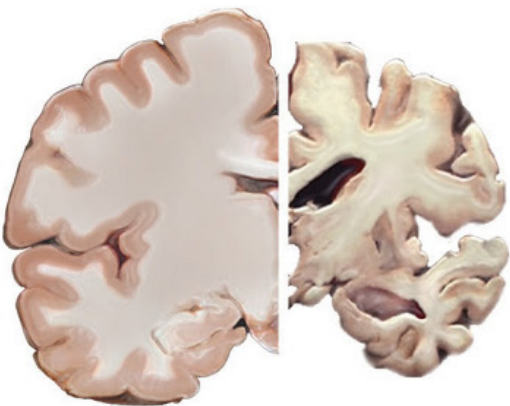
Dementia's roots

Dementia, the term used to describe more than 100 cognitive impairments [2], is Latin for 'out of mind' [3]. It is no wonder that there is still intense stigma surrounding a condition where we—doctors, family members, society in general—refer to people who are diagnosed with a form of memory loss as 'out of their mind', whether we know its roots or not.

Types of dementia

The main types of dementia can be classified as semantic dementia (SD), frontotemporal dementia (FTD), and the most widely-known, and the type that I mainly focus on within my research, Alzheimer's disease (AD) [3]. It was not until 1906 when Dr. Alois Alzheimer diagnosed the first patient with Alzheimer's disease. The patient was originally thought to be 'mentally ill' due to her memory loss, language problems, and unpredictable behavior. In a post-mortem, Dr. Alzheimer found clumps and tangled fibers within the patient's brain, and used these findings to explain her 'odd' behaviors [4].

Since Dr. Alzheimer's discovery in 1906, there have been strides taken in trying to understand the brain. Researchers know that 'the damage [in AD] initially appears to take place in the hippocampus and the entorhinal cortex, parts of the brain essential in forming memories. As more neurons die, additional parts of the brain are affected and begin to shrink.' [4] [figure 1] However, even with this information, and 114 years later, there is still no 'cure' for Alzheimer's disease - perhaps due to the very little funding that is put towards Alzheimer's research in North America. Based on an article written for the AARP in 2015, the Federal Government pledged 560 million dollars to Alzheimer's research. Cancer research received 5.4 billion. [5]

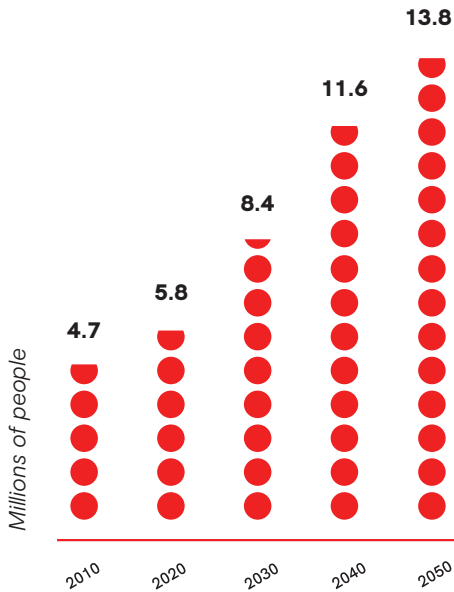


[Figure 1]

Source: Alzheimers and the Brain, Youtube Video, July 2nd 2019, https://www.youtube.com/watch?v=dWcdBOYy_bU&t=164s [22]

Figure 2

Projected number of people age 65 and older in the U.S Population with AD



Source: Adapted from data from Herbert et al. [23]

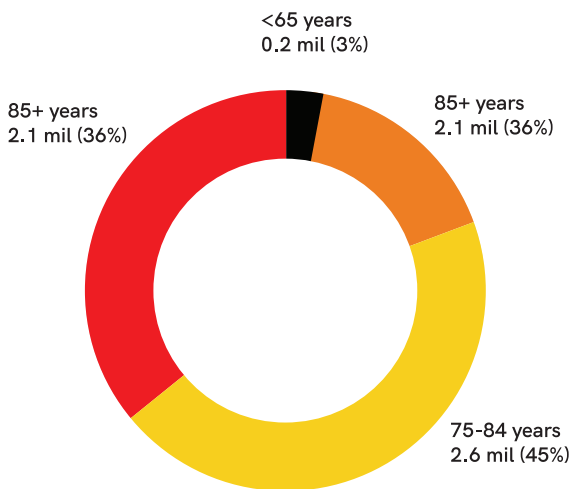
Facts and Figures

As we continue to live longer, the number of people diagnosed with Alzheimer’s disease is rising. Today, 5.8 million Americans are living with Alzheimer’s disease [1] — that is more than quadruple the number of people that live in Seattle (~744,955) [6], where this project was conducted. According to the National Alzheimer’s Association, nearly 14 million individuals will be diagnosed with the disease by 2050 [1] — that is nearly double the population of Washington State (~7.615 million) [6]. [Figure 2]

And while you might think that the number of doctors specializing in gerontology, the study of aging and older adults [7], is rising to meet the needs of individuals diagnosed with Alzheimer’s disease, Atul Gawande provides a shocking realization in his 2014 book *Being Mortal* that states ‘although the elderly population is growing rapidly, the number of certified geriatricians the medical profession has put in practice has actually fallen in the US by 25% between 1996 and 2010’ [8]. In 2016, the New York Times echoed this finding, reporting that in the state of Oregon, there is only one trained gerontologist per 3,000 people over the age of 75 [9].

Figure 3

Age of People with Alzheimer’s Disease



Source: Adapted from data from Herbert et al. [23]

Myths

Many people believe that dementia, especially Alzheimer’s disease, is inevitable as we age. The fact is that growing older does not mean that you or I will be diagnosed with dementia or Alzheimer’s Disease. However, being young does not mean you *cannot* be diagnosed. Forty-five percent of cases affect people ages 75 to 84, and while it is a small margin, 3% of cases affect people ages 65 and younger — that is nearly 200,000 people [4]. Figure 3]

What may come as more of a surprise is that even though neurons within the brain are dying until end of life, ‘memory impairment in Alzheimer’s Disease is far from total — people with AD have

some preserved memory capacities [3]. This study, conducted in 1998 by Fleishman and Gabrielli [10], found that individuals diagnosed with Alzheimer's Disease 'show normal performance' on tasks that do not require a conscious retrieval of information [3].

These 'areas of preservation' include priming tasks, such as 'fluently and expressively' playing the piano even though the individual does not remember that they were a piano teacher earlier in their life [3]. Upon reading this study, I finally understood why my great grandmother's penmanship was so perfect and started to consider if this concept could be used to help strengthen relationships between individuals living with AD and their care partners.

In 2018

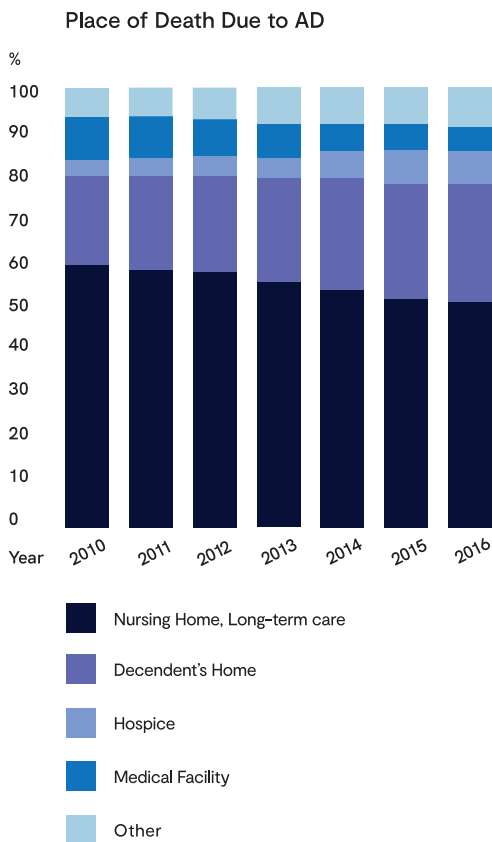
18.5

billion hours of informal care were provided by Alzheimer's and other dementia caregivers [1]

Options Once Diagnosed

Many people speculate that Alzheimer's Disease is a death sentence — that life no longer has the meaning it used to post diagnosis. However, individuals diagnosed with Alzheimer's Disease tend to live another 4-8 and even up to 20 years after diagnosis, depending on severity [11]. While there are a plethora of facilities that accommodate individuals living with Alzheimer's, such as Assisted living, Nursing homes, retirement communities etc, 90% of people over the age of 65, according to The American Institute of Architect's *2016 Home Design Trend Survey* [12], say that they wish to age-in-place. When a loved one is diagnosed with Alzheimer's disease, it is important to understand the cost and physical and emotional tolls that occur when deciding what option is best for the situation at hand.

Figure 4



Source: Adapted from data from the National Center for Health Statistics. [24]

Aging in place [AIP] is a concept that offers autonomy to older adults through safe and accessible design. AIP allows the aging population to sometimes have greater quality of life, especially when it comes to mental health. In 2019, the National Alzheimer's Association recorded that informal caregiving by family members or unpaid caregivers accumulated 18.5 billion hours of care [1]. There is promise that more folks diagnosed with dementia are in fact remaining in their homes until their death. [Figure 4]

While Aging in Place also saves \$16,000 per year [12], it is not always feasible for individuals living with memory loss and their care partners. Being a care partner for someone living with progressive Alzheimer's Disease can be emotionally and physically challenging and incredibly time consuming (ex: having to give up social events or even stop working). The person living with AD could also live alone and need 24 hour care (help going to the bathroom, getting in and out of bed, help with remembering to eat). Or, as their dementia worsens, it may be unsuitable for a family caregiver to continue providing care, or administer medicine.

This is when nursing homes come in to play for many individuals living with dementia. According to the 2018 National Alzheimer's Association report, 'at age 80, approximately 75 percent of people living with Alzheimer's dementia are expected to be in a nursing home compared with only 4 percent of the general population at age 80' [13]. Nursing homes, as Atul Gawande points out in his book, *Being Mortal*, were never made for with humans in mind. Nursing homes 'were never made to help people facing dependency in old age. They were created to clear out hospital beds—which is why they are called “nursing” homes' [8].

While nursing homes perhaps have a certain connotation attached to them, there is still evidence that many individuals living with Alzheimer's dementia end up in this type of facility because providing care in the homes proves to be too challenging due to their cognitive impairments.

How can these facilities be compatible for both treating old age and promoting quality of life? This is where I saw a leverage point — an opportunity to design art programming with and for nursing home memory units to help maintain or enhance the quality of life for folks who are living there.

Why Design?

I am often asked why, as a designer (and person under the age of 40), I am interested in working with and for this population. A lot of people find it 'odd' that a 26-year-old woman would want to work with the elderly. To me the answer is simple. I want, and thoroughly enjoy, to use my skills in order to enrich people's lives.

I will admit that, at first, I was nervous about entering this community as a 'designer'. Would a designer be welcomed in this space? Would people take me seriously? Was design even needed within the dementia-friendly community? Did I know enough about Alzheimer's Disease to make a lasting and successful impact? Was I too close to the topic?

That was when I met Marigrace Becker, Program Manager of Community Education and Impact at the University of Washington Memory and Brain Wellness Center. Since Spring of 2019, Marigrace has been one of the most encouraging individuals as I navigate designing with and for individuals who have been diagnosed with dementia.

As a visual designer by training, and design researcher, I believe that I bring an interesting and unique perspective to this space. My understanding of color theory, visual hierarchy, information design, affordances and other design methods helps me organize our interactions with and understanding of the spaces in which we live. This knowledge was and will be useful for my continuous design exploration. I will go into these methods in more detail in the sections '*Installations and Design Inquiry*' (p 20) and '*Workshops*' (p 34).

Original Design Inquiry

Using my design expertise, I was originally focused on creating with and for people living with Alzheimer's and their family caregivers. While this exploration would have therapeutic qualities, the goal of this design exploration was different from art therapy in a few ways and also reiterated in John Zeisel's book 'I'm Still Here'. Zeisel mentions that labeling engaging with art as art therapy does not encourage 'art experiences as an integral part of their [people living with Alzheimer's] daily life' [15]. The main goal of this thesis is to empower caregivers by designing the proper tools for them to engage in art-making as a new way to communicate.

While it is known that the brain shrinks when someone is diagnosed with Alzheimer's disease, 'memory impairment is far from total' [3]. This piece of information made me question if creative tasks, such as painting, drawing and collage could help form new ways of non-verbal communication between folks living with Alzheimer's disease and their family caregivers.

Using my design skills, I set out to create an in-home kit that would provide autonomy and structure to make in the home. Prior to the COVID-19 outbreak, I was planning to fabricate a personalized art making kit for a woman living with early stage Alzheimer's disease and her husband, who also acted as her care partner. However, due to social distancing restrictions, I was not able to continue down this initial route.

Current Landscape

More often than not, pharmacological approaches rank supreme when it comes to coping with and managing a diagnosis of dementia. Conversations tend to focus on the longevity of a person's life, rather than the quality. 'Medical professionals concentrate on repair of health, not sustenance of the soul' [8], leaving medicine's focus too narrow. While pharmacological approaches to dementia may be necessary, care partners must be empowered to implement non-pharmacological approaches within their daily routines.

I'm Still Here Foundation

John Zeisel echoes Gawande's notion in his book *I'm Still Here* when he states that 'we [society] need to see the person through the fog of the illness, and we have to employ as many nonpharmacological treatments as pharmaceutical ones' [15]. Zeisel created the I'm Still Here Foundation in 1995. The goal of the foundation is to implement non-pharmacological approaches to Alzheimer's Disease including poetry writing, museum visits and art-making in order to celebrate the whole person, not simply focus on their diagnosis. As Zeisel sees it, 'when art is a profound part of the everyday flow of life for people living with Alzheimer's, it offers a vibrant and extraordinary dimension.' [15] Rather than treating symptoms, Ziesel advocates for the person.



Figure 4: I'm Still Here Website [25]

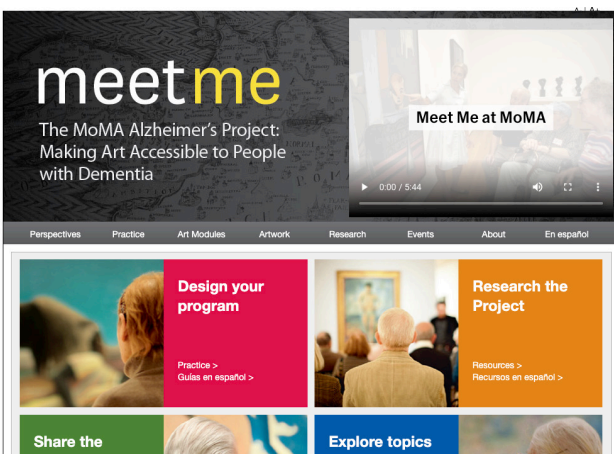


Figure 5: I'm Still Here Website [26]

Meet me at the MoMA: Alzheimer's Project

In 2006, with the help of John Zeisel, the Museum of Modern Art began the monthly program called Meet me at the MoMA. The program was funded by the MetLife Foundation and its main goal was to 'aim to contribute to an ideological shift in the way both institutions and individuals think about Alzheimer's disease.' [16] The program started by walking through a specific part of the museum — the group focused on four to five pieces of art and would discuss what they saw. Participants would then partake in art making sessions after the tour

the museum. While this was a great initiative, Meet Me at the MoMA appears to have become defunct in 2011.

Frye Art Museum's Creative Aging Program

In 2010, adapting the initiative of Meet Me at the MoMA, The Frye Art Museum developed the Creative Aging Program. Now in its tenth year, this program, run by Mary Jane Knecht, has been a huge success in Seattle. The Frye Art Museum, unlike the MoMA, is a much smaller museum, featuring quiet, serene spaces during the museum's 'open' hours. This allows for people with dementia and their care partners to engage successfully within the museum space. There are many facets of the Creative Aging program, with the *Here:Now* program being at its core. *Here:Now* 'is an arts engagement program for adults living with dementia and their care partners to enjoy a creative and relaxing time together in a supportive setting' [17]. This program is broken into twice per month gallery tours, and a six week, free of charge program, that includes a gallery tour and art making session.

Mary Jane allowed me to sit in on a *Here:Now* session this past February, where 3 groups of care partners and their loved ones living with dementia attended the session. For about an hour, we sat in the museum's gallery space and discussed three separate works of art, all under a collective theme, which prompted discussion between the group. Then the group went up to the art studio to participate in an art making session — the room is large and full of sunlight, making for a very welcoming feeling. A large still life sat in the middle of the room, where tables and chairs were placed in a semi-circle so that everyone had a different perspective of the center piece. A plethora of materials were at our disposal — everything from wood blocks to colored wires to foam. We each created our own artwork while classical music played in the background.

Seattle Design Festival





Cal putting together the installation at South Lake Union



Rendering of installation
Credit: Jeremy Barribeau

Installations + Design Inquiry

Research through Design at the Seattle Design Festival

During my grant writing class in the spring of 2019, I met Marigrace Becker, Program Manager of Community Education and Impact at the UW Memory and Brain Wellness Center. Marigrace opened my eyes to the amazing programming and opportunities to work alongside folks who were making huge strides in the world of dementia care in the Seattle area. Through Marigrace, I was able to partner with Elderwise and The Gathering Place. Together, we created an interactive installation at the 2019 Seattle Design Festival titled *Looking Forward*. The installation aimed to shift the dialogue surrounding and the stigma against dementia by showcasing artwork and narratives created by local individuals living with dementia at the two community organizations. During the months leading up to the festival, I was in constant contact with each non-profit organization making sure they signed off on every decision leading up to the festival.

In early August 2019, Mollia Jensen, an Elderwise volunteer, invited me to attend one of their day programs to see what goes on first hand. Eight individuals living with dementia gather for the day to engage in activities such as singing, dancing and painting. During my time spent with these people, I was inspired by their vibrant and lively personalities. Even the participants that were more reserved showed their character through their artwork. When it came time to paint, each participant was handed watercolor paper, paintbrushes and three colors of paint: red, blue, and yellow. Soft music was put on in the background and immediately, every participant focused on creating. On the other hand, I was so focused on what the end result would look like that I became anxious and nearly froze from panic. It was then that I realized that the Elderwise participants were not focused on what they would

Page theme

Looking Forward: An Interactive Installation ↗



Looking Forward is an interactive installation that encourages visitors to help make Seattle a more dementia-friendly city.

⊕ Add link

Created by

Cal Dobrzynski

18 backers pledged \$1,601 to help bring this project to life.

📅 Last updated August 14, 2019

Screenshot of the SDF
Kickstarter Campaign
Rendering: Justin Lund

Story

Overview

Looking Forward is an interactive installation that encourages visitors to help make Seattle a dementia-friendly city. *Looking Forward* aims to shift the dialogue surrounding and the stigma against dementia by showcasing artwork and narratives created by local individuals living with dementia. The goal of the installation is to show the community that by empowering individuals with dementia, we can begin to create a dynamic and inclusive city, where all members can thrive.

There are currently 107,000 individuals living with dementia in Washington State*—and another 320,000 people caring for these individuals. With dementia projected to increase 180% by 2040, many cities, including Seattle, are working to reframe the narrative surrounding dementia and what it means to live with memory loss. Those affected by dementia may experience loneliness and social isolation but fortunately, there are several charitable community programs, such as Elderwise and The Gathering Place, that are dedicated to making Seattle a "dementia-friendly" city. These organizations are currently reframing the diagnosis of dementia by nurturing creativity and "addressing what endures in spite of physical or cognitive changes." (Elderwise.org)

*Based on 2018 Statistics from the [Dementia Action Collaborative of Washington State](http://DementiaActionCollaborativeofWashingtonState)

Pledge \$10 or more

Behind the scenes images

Receive behind the scenes imagery from the Seattle Design Festival installation process

ESTIMATED DELIVERY

Sep 2019

0 backers

Pledge \$15 or more

Postcard

Receive the following:
-One (1) postcard with artwork created at the Elderwise Day Program
-Behind the scenes imagery

ESTIMATED DELIVERY

Oct 2019

SHIPS TO

Only United States

3 backers

Backer report

Screenshot of the SDF
Kickstarter Campaign

Horizon

You can use the brush of a Japanese Monk
or a pencil stub from a race track.

As long as you draw the line a third
the way up from the bottom of the page,
the effect is the same: the world suddenly
divided into its elemental realms.

A moment ago there was only a piece of paper.
Now there is earth and sky, sky and sea.

You were sitting alone in a small room.
Now you are walking in the heat of a vast desert

Or standing on the ledge of a winter beach
watching the light on the water, light in the
air.

Emily Collins





Artist: Jane Miller



It is a necessity that we understand, that we are different than any other. The world and our compassion, to see
Roger Stocker

It is a necessity that we understand, that we are different than any other. The world and our compassion, to see
Roger Stocker



Mollia from Elderwise and Cal in front of the Watercolor Wall



Elderwise paintings hung at the installation

make, but the process of making it. The *process* was what was important to not only them but to the volunteers leading the group.

The installation, funded by a Kickstarter campaign, showcased at the 2019 Seattle Design Festival Block Party in South Lake Union. The goal of the installation, *Looking Forward*, was to show the community that by empowering individuals with dementia, we can begin to create a dynamic and inclusive city, where all members can thrive. The physical fabrication of the space consisted of five free-standing structures which surrounded an interactive art-making station. Two of the structures were utilized to display artwork created at both Elderwise and The Gathering Place and two were built to provide the audience with background information about the two non-profit organizations. At the last structure, visitors could hang the artwork that they had created for others to view.

Throughout the length of the two-day-long block party, volunteers from Elderwise walked visitors of the installation through the process of wet-on-wet watercolor — the same technique used at the Elderwise day program. The installation was a success, not only in the large number of people that came to view and make art, but perhaps even more significantly, based on the conversations that were happening surrounding dementia and what it means to live with memory loss. The most inspiring conversation I heard was a mother explaining to her daughter why her grandmother often forgets her name. In this unique space, the topic of Alzheimer's felt destigmatized. Dialogue was opening up.

The research and take-aways from the installation at the Seattle Design Festival became a launchpad for my Master of Design thesis.



Jacob Lawrence Gallery



Installations + Design Inquiry

Jacob Lawrence Gallery Works in Progress Exhibit

Once I had selected my thesis topic, I was initially inspired by the creativity that lives within a person even after a diagnosis of dementia. As I began to do more research and thought about my great grandmother's experience of aging in place, I wondered if her built environment aided (or disturbed) her daily life.

This installation, *Thesis Works in Progress*, was held by the Master of Design cohort at the Jacob Lawrence Gallery at the University of Washington in December of 2019. At this installation, I wanted to use the space to display the everyday struggles that care partners and their loved ones go through and show how small visual changes within the home could enhance not only daily life, but also aid when art-making. The goal was to also show the visitors that we can 'change the environment to better suit us' [18] to avoid anxiety, lessen stress and promote well-being, both mentally and physically.

The objects within the installation were personified, giving the viewer better insight as to why objects were a certain color etc. *Note: these were not actual things that occurred between my great grandmother Doris and her son Chuck.*

Red plate: *'When Doris was diagnosed with Alzheimer's, they bought me, a bright red plate. I help her differentiate the table from the plate when Chuck is helping her eat.'*

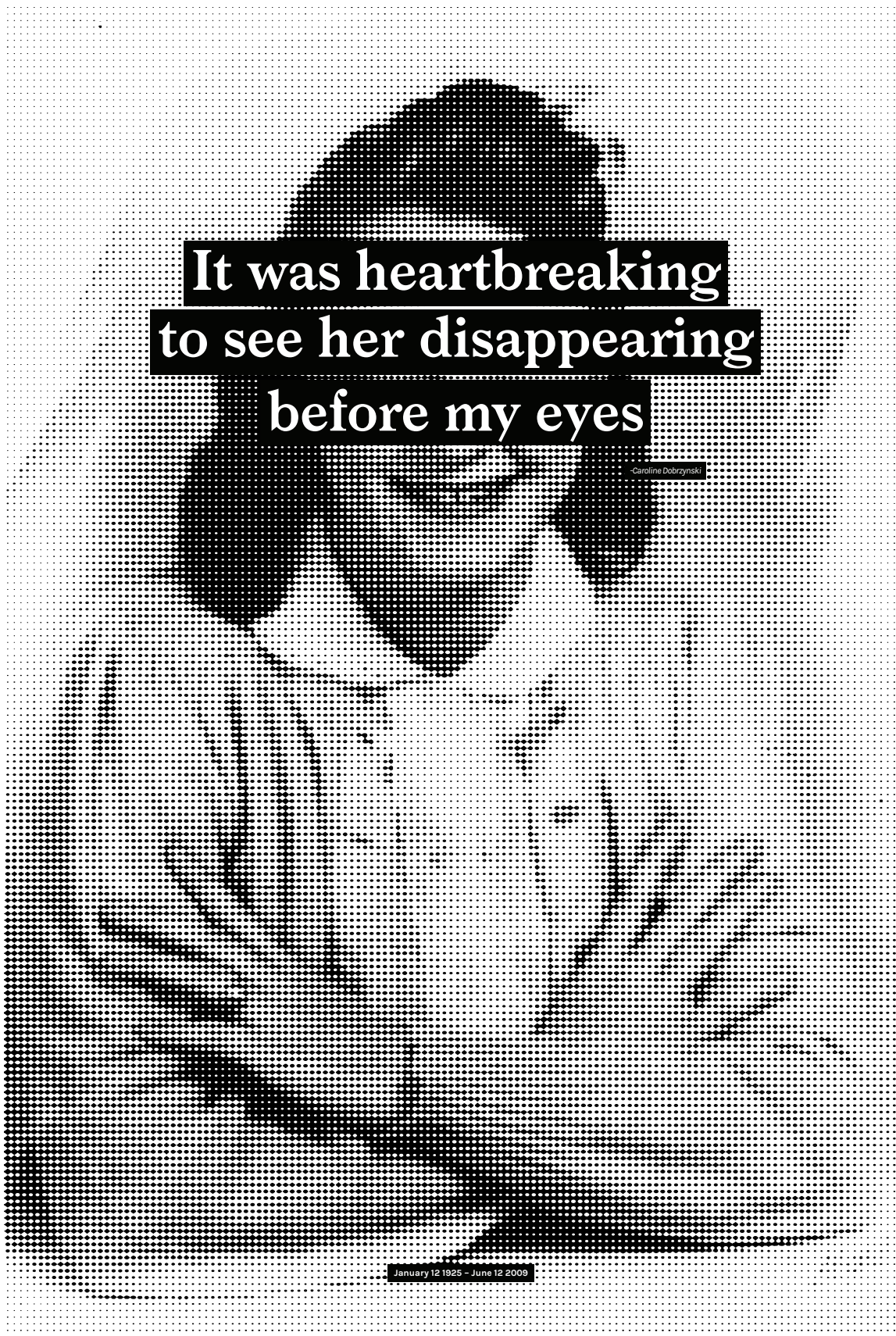
Based on a 2003 study at Boston University, people living with Alzheimer's tend to eat 25% more when given food on a red plate, due to its stimulating hue. [19]



A visitor at the Jacob Lawrence Gallery Installation



Visitors at the Jacob Lawrence Gallery Installation

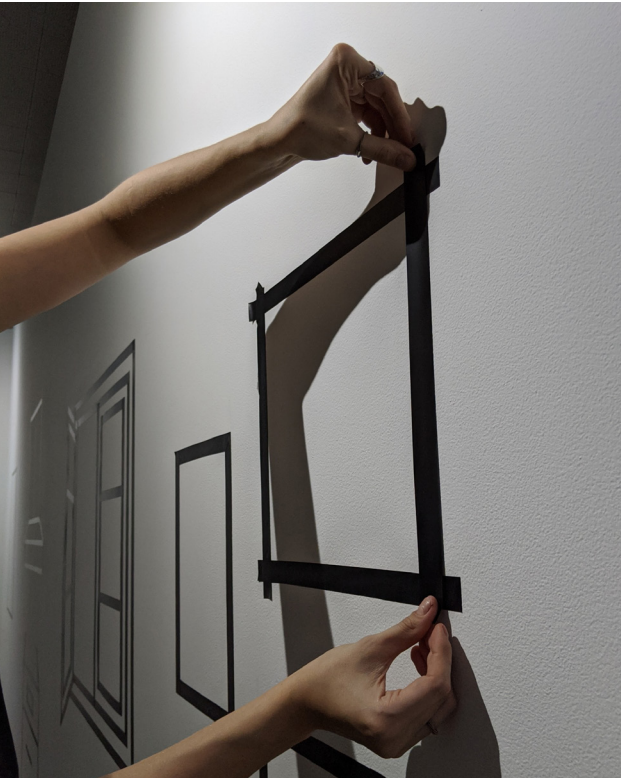


**It was heartbreaking
to see her disappearing
before my eyes**

Caroline Dobrzynski

January 12 1925 - June 12 2009

Poster created for the installation. This is an image of my great grandmother at her first job. It was manipulated in photoshop. The quote is from my grandmother, Caroline, Doris's daughter



Calcerating the installation at the Jacob Lawrence Gallery with vinyl tape

Open Window:

'Chuck keeps me open so that both he and Doris can get fresh air. It's becoming draining for Chuck to take care of Doris day-in and day-out. And since she can't go on walks anymore, I'm her only link to the outside world.'

One of the personification cards at the installation

Red cup and straw: *'Chuck bought me after Doris spilled her glass of milk a few times. Just like the plate, my color helps her spatially differentiate me from the table.'*

Empty Picture frames: *'There used to be a lot of family photos inside my frame, but Chuck removed them after Doris asked who the man in the photo was. Chuck couldn't bear to tell her it was him.'*

Window: *'Chuck keeps me open so that both he and Doris can get fresh air. It's becoming draining for Chuck to take care of Doris day-in and day-out. And since she can't go on walks anymore, I'm her only link to the outside world.'*

Stovetop: *'Chuck has to turn me off after every time he cooks to make sure that Doris doesn't touch me or accidentally turn me on'*

Fork and Knife: *'Doris can't use us anymore, but Chuck puts them on the table just-in-case she decides to mimic what he does.'*

The more an individual's dementia progresses, the more difficult it is to use utensils, as their dexterity can diminish.

Chuck's Meal: *'Doris always loved to eat this meal but no longer likes the way it tastes and rejects it when Chuck serves it to her. This is a difficult thing for Chuck to come to terms with... they used to cook and eat this meal together at least once a week.'*

Visitors of the installation were also given the opportunity to write down a note about their experience with Alzheimer's. Over the course of 2 hours, 7 anonymous and beautiful notes were written about individuals' experience with a loved one having dementia. Once again, this pace felt like it was opening up dialogue (this time internally) surrounding memory loss, just like the Seattle Design Festival installation did.

My grandmother
+ lost with Dementia
after suffering a stroke — the
two distinct qualities she didn't
lose were her ability to speak
piano from memory and her sense
of humor — both made Jane [↑] Jane
even before my mom will [↑] uniquely
suffer something similar + I want
to feel prepared to support
her, but it's never easy to know
how/where to begin. Thank you
for a moving story + installation
Cal! Very beautiful.

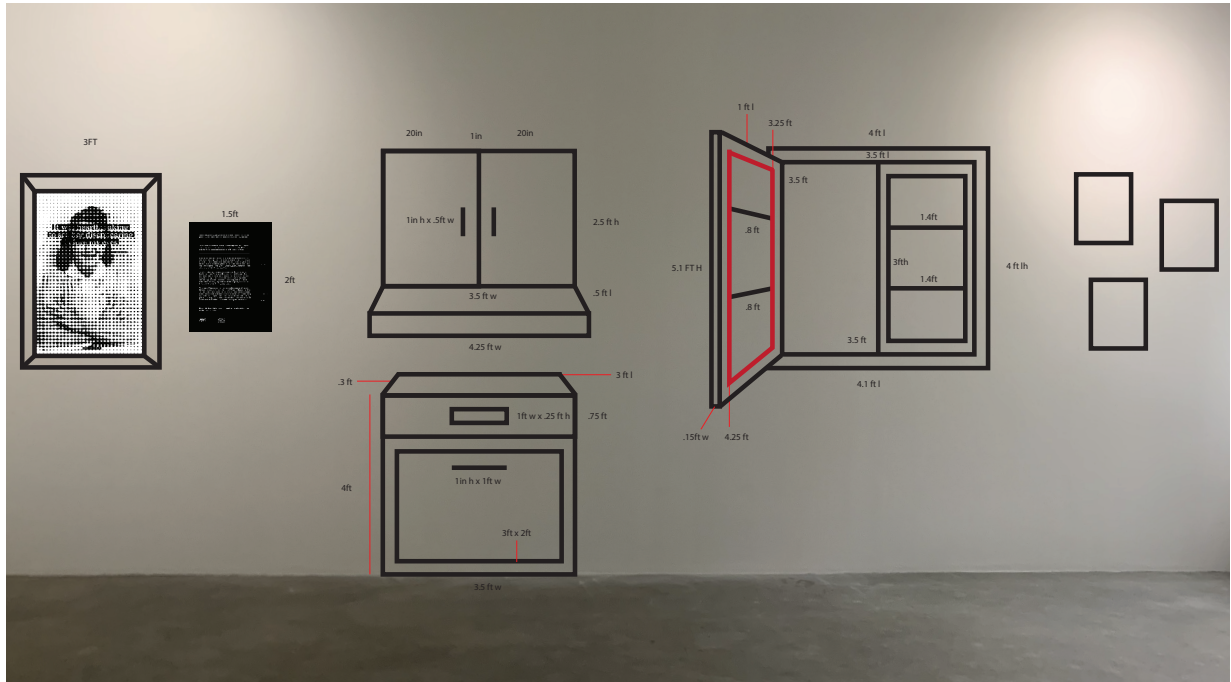
Visitor's note left in the notebook at the installation



Close up of the table at the installation



First mock up of the installation



Precise measurements of the installation



Volunteer practicing art project at Bridge's training



Close up of materials used at the Bridges training

Connections

Connection to community members:

During Autumn quarter 2019, Marigrace introduced me to Dr. Lee Burnside, who would later become part of my committee. She also invited me to speak alongside the Memory and Brain Wellness Center at two public presentations. Through these presentations, I was able to connect with Mary Jane Knecht who offered me a volunteer position at the Frye Art Museum in their Creative Aging program. It was through Lee and Mary Jane that I was able to connect with so many wonderful people and gain insight into where art could intersect with memory loss first hand.

Bridges Program at the Frye Art Museum:

Bridges is the Frye Art Museum's offsite art-making program. As a volunteer, I attended a Seattle-based care facility where I worked alongside a resident of the memory care unit. For four weeks during February 2019, I was paired with the same artist who was living with dementia and also had visual impairments. This interaction was new for me. The artist, (I will call her B), was very interested in projects that allowed her to touch and feel the materials in a three dimensional way. Even though B couldn't see what she was making, she could feel it — and witnessing that was amazing. Throughout the four weeks I was able to spend with B, my knowledge of sensory and tactile materials began to grow and B and I were able to connect in new ways. As Ellen Lupton puts, 'sensory design has the power to forge new languages' [20].



Cal assisting an artist during the Frye's Creative Aging Program, Bridges



Workshops + Design Exploration

My experience volunteering with Bridges through the Frye Art Museum was useful when it was time to run my own workshops. Prior to the outbreak of COVID-19 in North America, I was able to successfully run one in-person workshop at a Seattle-based memory care unit, Kline Galland Home. The main purpose of this workshop was to gauge what types of materials folks were interested in using based on the art therapy notion of 'materials as language.' [21] Based on the fact that the 'field of Art can esteem certain work and materials (e.g., high art, fine arts) and disparage others (crafts as "low arts")' [21], I was interested in seeing whether the participants were affected negatively or positively by the materials they were given to use. However, it was important that I did not consider this type of workshop 'therapy', as I am not an art therapist and wanted to encourage the participants to engage in this workshop in a social context.

The workshop did not have a set duration, and residents of the memory care unit could come and go as they pleased. The main reason for this was because I wanted to gauge how long residents would be interested in engaging in an activity. Out of the 10 participants, roughly five stayed for 30-45 minutes, two for 60 minutes, two fell asleep in their chairs and one stayed at the table and made art for nearly 1.5 hours. The level of engagement was vastly different; however, based on the majority of folks who left at the same time, I found that limiting the art making sessions to 30 to 60 minutes for most residents made sense. Of course, there are cases when residents want to create for over an hour, which proved to be true during this workshop session.



Resident using pastels to create a painting



Two residents working together to create a composition with cut paper

Other insights gathered were:

- *Plan for a certain time of day:* The session I held at Kline Galland started at 11 am, which was too close to lunch time. Participants became distracted by other residents eating etc.
- *Provide multiple materials:* Each participant wanted to use a different material - from cut out paper, to pipe cleaners, to pastels to watercolors.
- *Set up space prior to the activity:* During this workshop, I tried to set up the space once all residents were sitting down at the table; however, this proved to be difficult, as there were 10 residents and only I was able to set up the space.
- *Provide a prompt:* This workshop did not provide a prompt, which proved to be difficult for about 4/10 participants. While not everyone needed a prompt, having guardrails in place would be beneficial. *Ex: one participant needed to use a coloring book sheet that already had a predefined image that the participant could color in.*
- *Engage the senses, but don't overwhelm:* Due to the time of the workshop, the space the workshop took place was very stimulating - there was about 10 other residents in the room, as well as staff, which made the room quite loud. However, there was nice classical music playing and bright sunlight coming in from the windows, which helped stimulate the residents in other ways.

Intended Case Study

This workshop and the insights gathered were meant to inform an in-person case study that I was preparing to run in March of 2020. A call for participants was sent out through the UW Memory and Brain Wellness center at the end of February.

The criteria for entering the case study was as follows:

Qualifications:

- You are a family caregiver (spouse, sibling, adult child etc.) taking care of a loved one living with dementia, specifically Alzheimer's, in a domestic setting (ex: your own home).
- You and your loved one live in King County, WA

Potential Benefits:

- Participating in this case study will hopefully offer you and your loved one living with Alzheimer's disease new ways to successfully communicate using non-verbal methods.

Participation Involves:

- Three (3), 1-hour art making sessions in your home
- One (1), 30-60 minute intake session with both participants (in-person)
- Three (3), 30-60 minute interview sessions with both participants (in-person or via phone)
- Keeping a log during art-making activities
- The ability to be recorded throughout the process for research purposes (photos, video, etc.)

Through the call for participants, I was able to connect with the spouse and primary caregiver of an individual who is living with early-onset Alzheimer's in King County, Washington. Through a phone conversation in the beginning of March, we set up an in-person meeting for later in the month. While this case study was set to begin at the end of March, I was not able to visit in person or continue this case study due to the COVID-19 outbreak. Due to the global pandemic, I was no longer able to work in-person with these folks and due to a prior trip, had to self-quarantine.

Looking for alternatives to conducting the case study in person, I tried to think of means to get materials to the participants to continue the case

study. During this time, there was (and still is) fear of cross contamination, so I was unable to send anything to households. I also had to take a step back and realize that this case study was not their primary concern at the moment, nor would it be for the foreseeable future. Because individuals living with dementia are immune-compromised, they are very 'high-risk'.

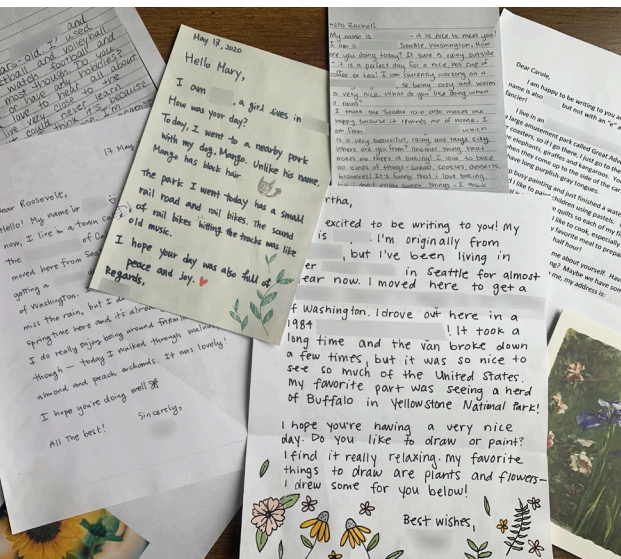
Social Isolation due to Global Pandemic

This global pandemic has left individuals living with dementia and their care partners more alone than ever. Not only are individuals living in domestic settings isolated, but folks living in nursing homes and assisted living facilities are as well. The three 'plagues' of nursing home existence are boredom, loneliness and helplessness [8]. These feelings exist normally, even without a global pandemic...now think about how intense these feelings are, given the current climate. Speaking with one Seattle-based home, residents are not allowed to socialize with other residents for fear of contaminating each other. They are only allowed to fraternize with the home's staff. Visitors are also not allowed.

COVID-19 also forced the Fry's Creative Aging program to cease for the time being, and the UW Memory and Brain Wellness Center could not continue in person activities or programs. As of June 12th, 2020, these programs are still closed.

Pen-Pal Program

Through reading a slew of articles about how isolated nursing home residents are during this time, I began to brainstorm ways that community members could interact with residents in the Kline Galland Home. Through an ask via social media (Instagram and Facebook), I was able to get 15 individuals to sign up to write letters to Kline Galland residents. Five participants have been writing to the same residents every week, while 10 individuals write to new residents each week. All letters are sent to my residence before they are



Pen-pal letters sent to Kline Galland Memory Unit

sent over to the memory unit, for quality control. For instance, making sure the letters are not too long, that writing did not include terminology the residents would not understand, that no profanities were used etc. The manager of the memory unit reads the letters along with the residents and also helps write back to some participants if the resident is interested in maintaining a relationship.

Art-Making Program in a Nursing Home Setting

Overview:

This section will discuss three of the eight virtual art making sessions that were held at Kline Galland Home within the Memory Unit and how the manager of the memory unit will continue these activities on her own.

Projects included the following:

May 22nd: Monet inspired collage

May 26th: Picasso inspired Clay

May 29th: Degas inspired Pastel

June 1st: Hannah Hoch inspired collage

June 3rd: Mask Making

June 9th: Monet Watercolor Postcard

June 10th: Toulouse-Lautrec Poster Making

Programming

Along with the Pen-Pal program, I started to wonder if I could alter my case-study so that I could continue to work with the residents of Kline Galland in a virtual space. With the help of Dr. Lee Burnside and Heather Geier of Kline Galland, we were able to successfully set up the programming in a digital setting via Skype.

The idea stemmed from my original question: how can art-making enhance non-verbal forms of communication between people living with AD and their familial caregivers? The question now shifted to: how can art-making enhance non-verbal communication between individuals living with dementia in a nursing home and their care partners (staff, etc)?



Residents at Kline Galland home working on their Matisse inspired collage



Final compositions created by 4 different residents

The main goals of the virtual art-making sessions were:

1. To see if the instructions were easy for Heather, the manager of the memory unit, to follow,
2. If this programming would work with multiple participants all at the same time,
3. If this programming empowered Heather and other caregivers to be able to host art-making sessions and eventually without my direct guidance via Skype.

Methods

Two weeks before programming started, Heather and I talked about what these sessions could look like. Based on our conversation, I then began to brainstorm activities and logistics.

Questions included:

- How long should each session last? Giving a time frame would be important for the care partner to structure each session
- What materials should be used? Should there be a variety or should each session focus on a set of materials?
- How detailed should instructions be?
- How can sensory stimulation be involved? Should audio be included? Would projects conducted outside be feasible?
- What should the flow of the session look like? How could this programming keep residents focused? And be stress free for the care partner?

First, I identified what portions of *Meet me at the MoMA* and the Creative Aging Program at the Frye Art Museum were successful. Both programs offered insight into artwork which prompted discussions between the participants. I thought that this would be a great way to engage the Kline Galland residents at the beginning of a project. While they are not able to go to museums on a regular basis (especially since the start of the COVID-19 pandemic), introducing residents to artists and their works seemed like an engaging way to reach participants at their place of residence.

I then began thinking about the time frame of projects. After speaking with Heather and considering insights from the first in-person workshop, it was clear that not every session should be 60+ minutes long. However, there are residents who are interested in participating in art-making for over 60 minutes, as demonstrated in the first workshop. Because of this, I decided that projects should be cataloged by the estimated amount of time the actual art making was projected to take. Projects were split up into three categories: 30 minutes, 45 minutes and 60 minutes so that Heather could decide, based on her schedule, how long a session should last.

I then spoke with researcher Gloria Puurveen from the University of British Columbia about her experience moving in-person art-making sessions to the online/virtual realm. She found that transitioning an in-person art-making session online did not always translate, as the online/virtual sessions had to be more tailored. Based on this, Gloria proposed that having one project with specific/limited materials was more successful when working in a virtual space. This altered from my in-person insight of 'providing multiple materials'.

I also spoke with Gloria about types of materials—whether she had found a difference in success between using 'high-end' and 'low-end' materials

and supplies. While she said that she was not necessarily an advocate for 'high-art' materials, she did find that providing age-appropriate materials was the most successful route. For instance, instead of providing crayons that say 'kids', or 'Crayola crayons', provide crayons that do not tantalize the artist, such as the ones you see below. Based on Gloria's insights, when choosing materials, I made sure that all of them were not childish or 'for kids'.

Virtual Sessions:

For the first virtual art making session, held on May 20th, Heather gathered four residents at 2pm to make art in the Kline Galland Memory Unit. Due to COVID-19, only a handful of residents can be around each other at any given time and must sit at their own table. Each artist was ushered to their table, where Heather had set up materials prior to the start of the session. Materials for each artist included ~20 pre-cut Matisse-inspired shapes, a 9x12" canvas board, craft glue sticks, mod podge sealer and a foam brush.

The goals for the first session were as follows:

- Have the care partner guide, not lead the resident during sessions
- Empower the manager and the resident to create on their own (without me there via Skype)
- Provide instructions that were self explanatory
- Provide the care partner (Heather) with the tools they need in order to be successful
- De-brief and iterate on project prompts so they work for the caregiver

Each resident was paired with a care partner from Kline Galland to help them if needed. I was able to virtually pair (via Skype) with Resident #1, who did not seem to have an issue with the video chat. However, this might not be the case for every individual living with dementia and careful consideration should be taken when using a video chat in order to speak with people living with dementia. For instance, prior to starting the activity, a different resident walked up to the screen and said *'why are you hiding from me?'* to the screen. It seemed that the resident could not understand how I was on the screen but not physically present.

It should be noted that Heather obtained permission to audio record the session with participant #1 for research purposes. This did not violate HIPAA regulations.

When the participants were ready, Heather began to walk them through the project based on the instructions I wrote.

The instructions included:

- The project name
- The amount of time the project was projected to take based on perceived difficulty
- Materials needed to achieve the project (including pre cut shapes)
- Information about what a collage is
- A bio on the artist, Henry Matisse
- Questions to pose to the artists, including open ended and yes/no questions
- Four examples of Matisse's collages

Heather began with introducing the project name, 'Matisse Inspired Collage', and went on to talk about what a collage is. Heather then asked the participants to look at the examples of Matisse's collage one at a time (there were 3 examples). She began to pose questions to the participants, such as *'What colors do you see?'*, *'Would you hang this in your room?'*. A great insight that will be valuable for future programming is to provide both open ended and yes/no questions for residents to respond to.

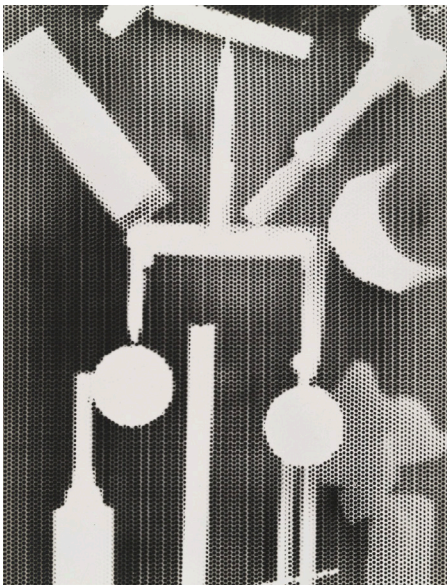
While the session was in the 30 minute category, the entire session lasted ~60 minutes. The first 25 minutes included introducing the project, and discussion. While three videos were provided to watch for the residents, in order to increase sensory stimulation, Heather did not show the residents the videos during this session. Each artist spent about 30-35 minutes creating their artwork, and they all stayed for the duration of the activity and were actively engaged.

Outcomes:

- Each artist was able to finish their work and maintained interested and alert for the duration of the project (~60 minutes)
- Resident #4, who usually does not do well in group settings, was able to calm down and finish her project within the group setting.

Insights from debrief with Heather:

- Reduce the amount of copy in artist bio and use less complex vocabulary when describing the project: i.e. some terms in the collage write up were confusing for residents.
- Do not have the care partner place all materials first if providing a prompt, as residents get distracted - i.e. one artist started placing all of the cut out shapes when Heather was reading the artist bio.
- Make color copies of all art pieces so that each resident has their own to look at for discussion.
- Make artist bio in large font for residents to read - cannot see mouths to read lips when care partners are wearing full PPE (face mask, face guard etc)
- Craft glue sticks don't work as well as regular glue sticks (thicker tube, less likely to fall out)
- Canvas boards did not hold regular glue, use plain stock paper next time



Session #4

Between sessions 1 and 4, Heather and I discussed insights that were valuable to the rest of the programming. The fourth session took place on May 29th at 2pm in the Kline Galland garden, directly outside of the memory unit.

The project revolved around Man Ray and his photograms, or rayographs, as he so humbly called them. Heather walked through the beginning portion of the project, which included looking at 3 very abstract rayographs. While only two residents created during this session, four other residents sat outside to listen and watch what was happening. Because there were only two residents participating, the discussion was less rich than normal. The abstract forms in the rayographs (see compositions to the left) were also difficult for the participants to discuss.

After the discussion, Heather moved both participants into the sun in order to make their photograms. The 5x7" paper is sun-sensitive and when exposed to light changes color. Heather then passed out natural materials she had found during the session set-up. Materials included flowers, leaves, sticks etc. Because the paper exposes quite quickly (only 2 minutes needed to expose the paper), Heather decided to move both participants back in the shade after the first composition they created so that they would have more time to arrange their materials on the sun-sensitive paper.

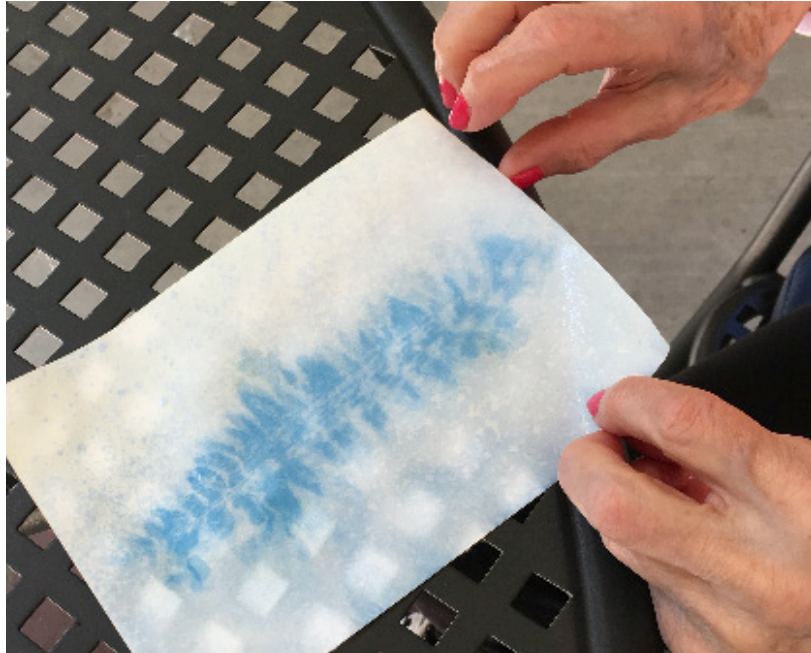
The residents that participated were very supportive of one another, telling each other 'Wow! You did so great!'. Resident #1 even walked over to another resident who was not participating in the art making session to show him her creations.

See next page for results

Rayographs courtesy of
© 2020 Man Ray Trust
/ Artists Rights Society
(ARS), New York / ADAGP,
Paris



Resident placing found natural objects on the sun sensitive paper



Final composition after exposed for ~2 minutes





Cal on Skype and Resident #1 creating a mask



Resident #4 painting her mask

Session #6

The last session that I will discuss in this paper was held on June 3rd, 2020. At the beginning of this session, one of the residents asked Heather, *'where are those things [referring to the Matisse inspired Collage] we made? Are they safe?'*. It had been about 2 weeks since the residents created their Matisse Collage, which was a great sign. The residents were taking pride in their work!

This project was different from all of the other sessions — it did not have a core artist for the residents to learn about or discuss one type of work. Instead, the project focused on a border category of art, mask-making. The videos were also all very educational — clips from SmartHistory, Khan Academy and the MET were used to provoke discussion. To my surprise, the residents loved this type of video and were very engaged, even during the 6 minute video on conservation of an Alaskan mask. Two of the videos were conversation based and the residents seemed to interact with them more than when videos only had a solo voice speaking. Resident #1 also remembered a very minute detail from the Khan Academy video. When prompted 5 minutes later, she exclaimed, *'that mask was 3,000 years old!'*.

The residents and Heather then discussed 3 different painted masks. The participants seemed to enjoy the colors and symbols on the mask, saying that they were *'exciting'* and that they were painted with *'an interesting use of color'*.

Heather then placed white fabric on each of the participants' tables as well as a paper mache mask, pre-filled paint wells with 4 different acrylic paint hues, a water cup, and paintbrushes. Residents were told that they could also add textural objects when they were finished painting, like colored flowers and feathers. Classical music was then turned on and resident #1 started swaying her head along to the tune. As she began to dip her brush into the paint she exclaimed, *'We have a lot of jolly fun ahead of us!'*.



Resident #3 + #4 painting their masks

When the session was over, Heather texted me this statement, “The mask making went incredibly well. Everyone was SO proud of their mask after and loved the pictures that I took of them. I left the masks on the table and a big group of ladies gathered around it all discussing the masks and complimenting them.”

Now that eight sessions have been successfully completed, the overarching flow of the programming appears like this:

Prepping:

~15-30 minutes

- Care partner reviews program guide
- Care partner creates their own artwork to learn how to use the materials
- Care partner gets all materials for the project ready
- Care partner gets seating arrangements ready and brings residents to their tables

Socializing and Educating:

~25 minutes

- Review project with residents
- Discussion about 1st piece of art - each piece is printed out for the residents
- Care partner asks residents questions - open ended and yes/no
- Discussion about artist (if applicable)
- Watch biography video (~2-6 minutes)
- Discussion about 2nd-3rd piece of art
- Watch 1-2 videos if applicable (~2-6 mins each)

Making:

~30-60 minutes

- Resident begins to engage in art making
- Care partner encourages them throughout the process with words of affirmation and guidance if needed

The insights gathered from these virtual sessions will influence further programming, including providing 'kits' to Seattle-based memory units. The Kline Galland programming had a budget of \$300 for a plethora of materials and could conceivably be funded by a grant. Heather, the Kline Galland Memory Unit Manager, will also be distributing the programming to other activity coordinators within the nursing home setting. It will be interesting to see how the programming has to alter based on cognitive ability, or if the programming has to alter at all.

As mentioned prior in the 'Why Design' section, it was important for these activities to not feel like a form of 'therapy'. Ideally, these projects will be done multiple times per week and care partners will weave them into daily routines for a handful of memory unit residents at Kline Galland.

The design of the programming was different than that of a traditional art therapy session. Neither myself nor the Kline Galland Manager, Heather, are art therapists, not do we claim to be. The programming was created with this in mind. The programming is heavily educational and engages at least four residents in a social setting in hopes that communication will strengthen, making residents will feel a sense of worth in their daily life.

A total of eight sessions were held before this paper was published.

Opportunities + Future Work

My initial plan of action was to produce a case study and design in-home art-making kits for 1-3 Seattle-based individuals living with Alzheimer's disease and their familial care partner. While everything was on track in late February and early March, the impact that COVID-19 has had on the dementia-friendly community in Seattle has been severe. The Frye shut its doors to the Creative Aging program in the beginning of March and the UW Memory and Brain Wellness Center canceled events soon after. I was not able to complete in-person case studies with individuals due to compromised immune systems and the Washington state 'stay at home order'. It felt like my research was coming to a complete stop — and it felt like that for some time.

However, with guidance from Dr. Lee Burnside, I was able to continue my research to some extent in a virtual setting with Kline Galland Home within their Memory Unit. The kits evolved into programming that I will be testing at a variety of memory care units throughout Seattle in the future.

While a lot of my thesis did not go according to plan due to the COVID-19 outbreak, I am looking forward to continuing my research throughout the next year. I will be using my findings to apply for a workshop at the Dementia Lab Conference, which is now set to take place in January 2021 at Emily Carr University in Vancouver. I am planning on testing out the art-making program with researchers, doctors, designers, artists, people living with dementia, their loved ones and caregivers if accepted into the conference.

If testing the program continues to be successful, I am hoping to translate all of the programming into a website that care partners can access for free. I can also see this web presence expanding into an outlet where care partners could share other resources, including self initiated art projects.

Acknowledgments

I would like to thank my committee, Kristine Matthews, Annabelle Gould, Dr. Lee Burnside, the Division of Design, and Ann Langford-Fuchs for their guidance.

MDes 2020 Cohort: Jeremy, Jeremy, Justin, Piper, Samer (and Elijah).

Heather Geier and all of the residents in the Kline Galland Memory Unit for participating in the in person and virtual art making sessions.

Marigrace Becker for her generosity and insight, University of Washington Memory and Brain Wellness Center, Elderwise, The Gathering Place, Momentia and every individual involved in Seattle's dementia-friendly community.

Mary Jane Knecht and Carmen Ficarra from the Frye Art Museum for their generosity and allowing me to Volunteer for the Bridges Program.

My grandmother, Caroline Dobrzynski, for all of her stories about my great grandmother, Doris.

Philip Carpenter, Jeremy Viny, Lucy Copper, Samer Fouad and my father, Mark Dobrzynski (who flew all the way from NJ last minute), for helping with the Seattle Design Festival fabrication.

My partner, Paolo Manalo, for listening to my crazy ideas, his help with my installation in the Jake and for being insanely supportive throughout this entire process.

Taylor Miles, Coreen Callister, and Natalie Leonard for always providing thoughtful advice.

Roark Congdon, School of Architecture, for taking a chance and allowing me to take his Rhino and Digital Fabrication classes to prepare for the Henry exhibit (maybe next year?).

The Doby Family for their continued support and hilarious text messages.

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APPENDIX



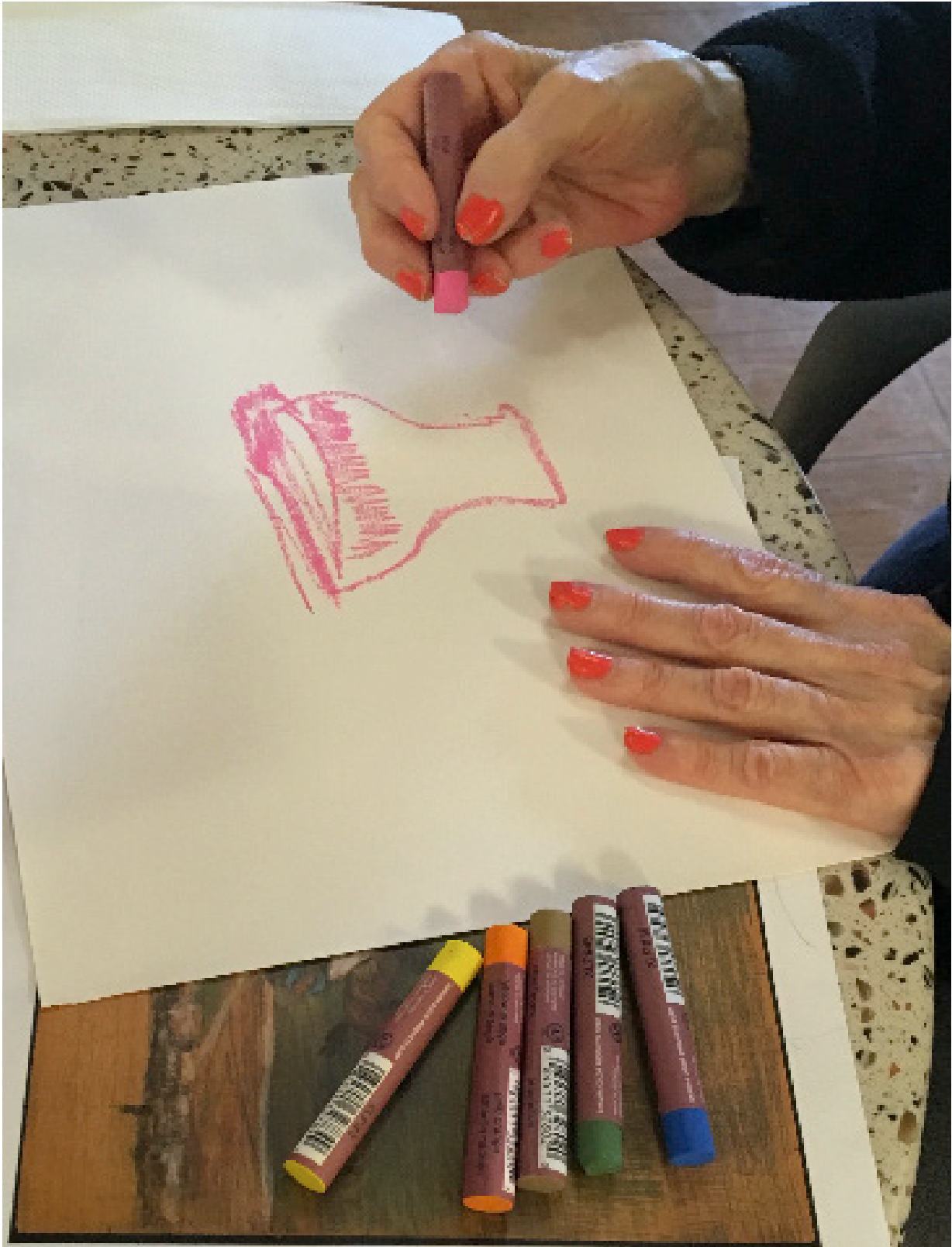
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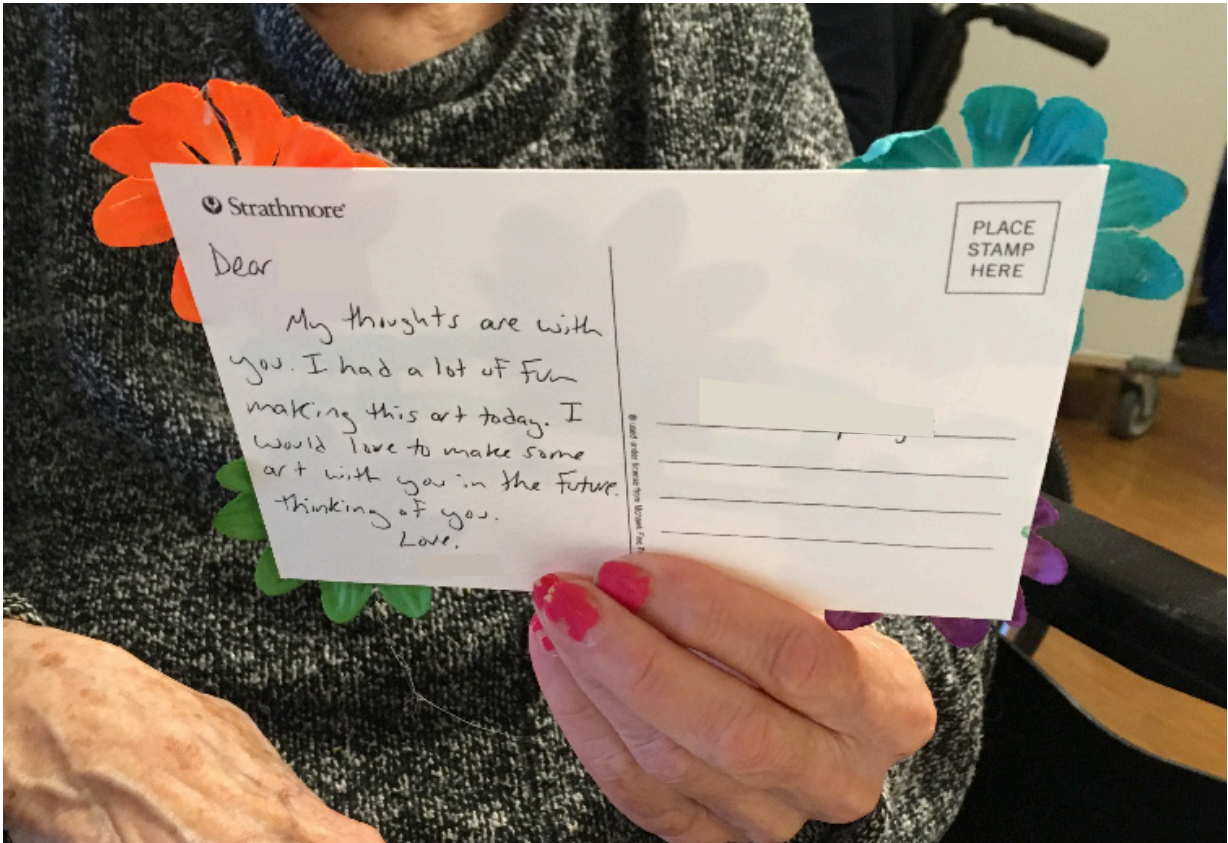
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