APHASIA

Empathetic Learning through Exhibit Design

Isabella Blanco is a multimedia exhibit designer and artist from New York City. She graduated from the Rochester Institute of Technology with a BFA in Industrial Design. Her interests lie in the use of experiential learning to bridge gaps in understanding and facilitate discussion concerning underrepresented groups.

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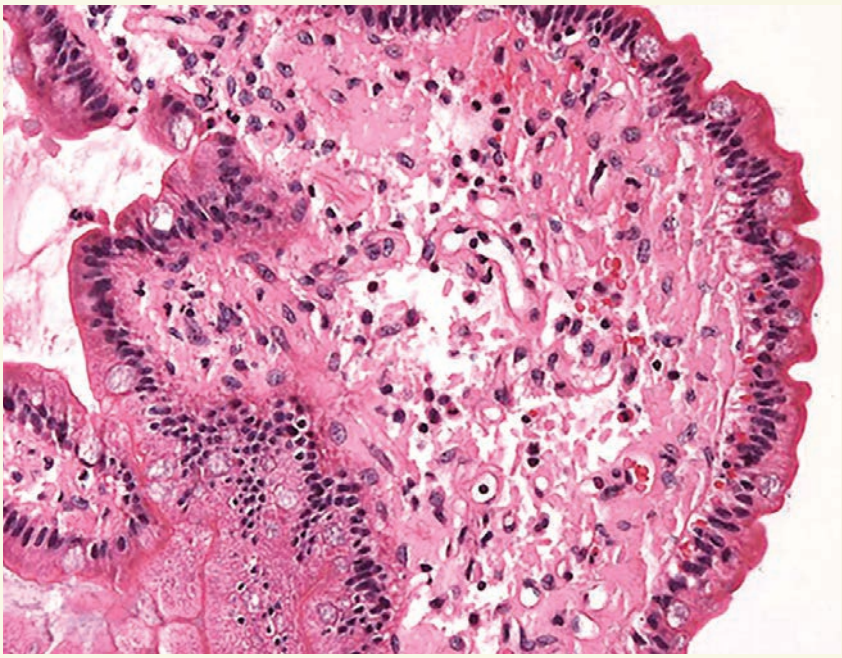
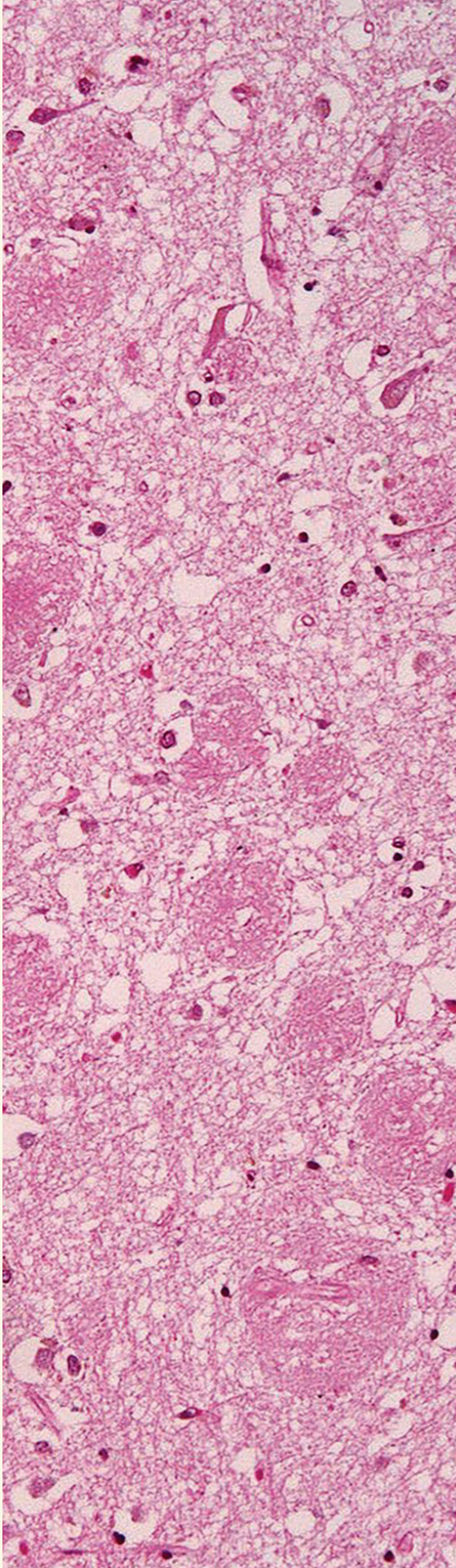
What is Alzheimer's?

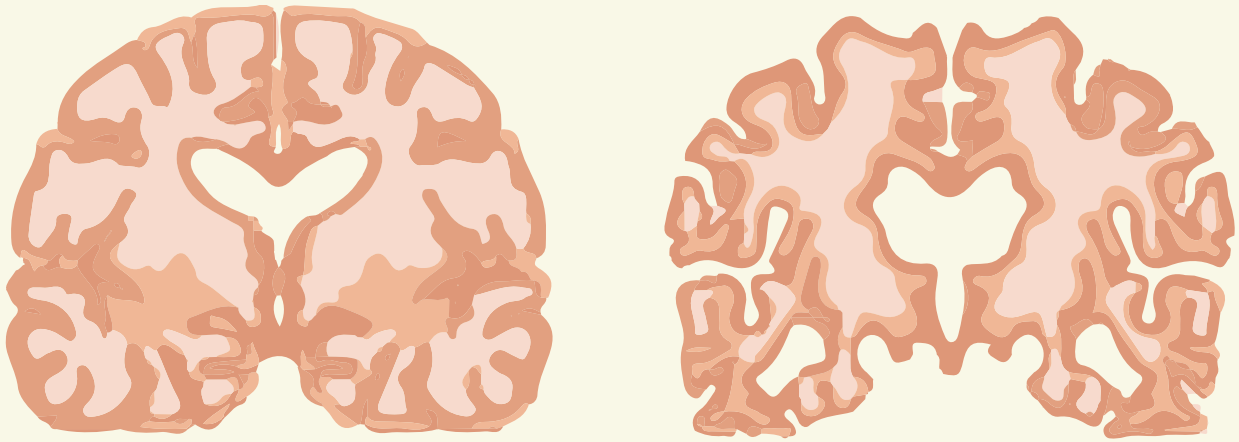
Alzheimer's is a degenerative brain disease comprising most dementia diagnoses. It can cause a wide range of physical and cognitive symptoms but is primarily associated with memory loss. These symptoms can start slowly, but will worsen over time. There is no current cure.



A magnified photo of homogeneous pink amyloid deposits between cells

There is little concrete understanding about the onset process of Alzheimer's. However, during the disease, abnormal proteins called amyloids are created and form clumps, or plaques. These affect the nerve cells of the brain and can cause them to die and form tangles. While we don't know for sure what causes it, major risk factors for developing Alzheimer's include old age, genetics, and social isolation, among many others.





A scan of a healthy brain versus one with moderate Alzheimer's Disease

About **1 in 9** people in the United States age 65+ have Alzheimer's.

6.9 million people are estimated to live with Alzheimer's.

The lifetime risk for developing Alzheimer's at age 65 is **21.1%** for women and **11.6%** for men.

Via Alzheimer's Disease Facts and Figures 2024 Report by the Alzheimer's Association

Why it Matters

The facts and figures often paint a bleak picture. It is human nature to shy from topics of loss and pain that feel larger than us. Additionally, the stigma of age can discourage younger people from entering dialogues on sensitive topics. But to move away from those with Alzheimer's is to leave them vulnerable when they need us most.

When my Lola was first diagnosed with Alzheimer's, everything felt so uncertain and scary. But when she moved to the apartment next door, my perception of the disease and her quality of life changed completely. Being close to loved ones and engaging in activities everyday makes all the difference.

Problem Statement

How can we empower other young people by offering an alternative perspective, and encourage a more open dialogue that focuses on support instead of fear?

Research

Sources

I spoke to experts spanning the medical, professional care, and grassroots volunteering fields to learn their perspectives on the disease, as well as recent literature.

Michael Parsons, PhD
Neuropsychologist at MGH Harvard

Susanne Bengtsson
VP of Family Supports at CaringKind

Taylor Thum
Author of "Alzheimer's Disease, Media Representation, and Audience Reception"

THE UNIVERSITY OF TEXAS AT DALLAS

Fairfield UNIVERSITY

Alzheimer's Foundation of America
Students on the executive board of AFA school chapters

Secondary Sources

A Pocket Guide to Understanding Alzheimer's Disease and Other Dementias by Dr James Warner and Dr Nori Graham

Alzheimer's disease, media representation, and audience reception by Taylor Thum

My Story of Alzheimer's Disease by My Story Films

"The mainstay of dementia care is not about drug treatment. Providing practical and emotional support, advocacy and information to the individual with dementia and their carers and family is a huge part of dementia treatment."

"People and sometimes even caregivers can think people with Alzheimer's are doing bad things on purpose, but they aren't scheming, they just completely forget."

What Does Alzheimer's Look Like?

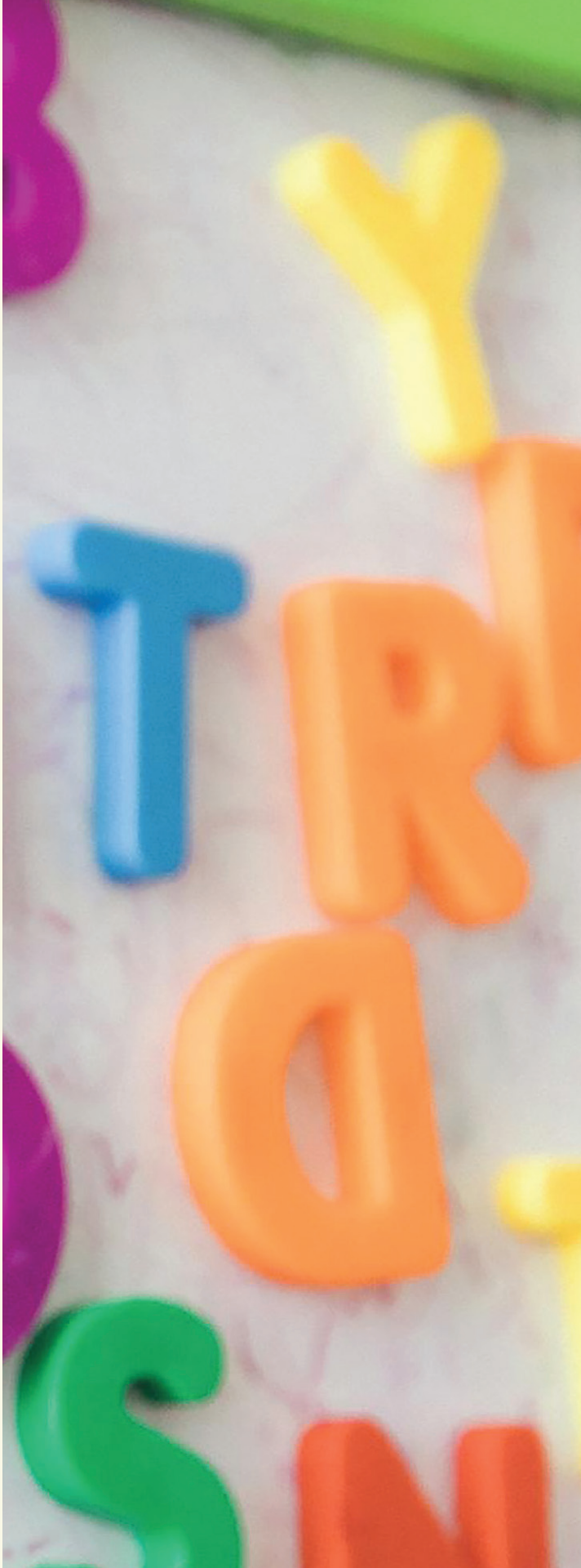
While memory loss and confusion are easily recognized hallmarks of Alzheimer's, there are other common sensory symptoms.

Loss of ability to form long term memories

Seeing persistent hallucinations

Visual and auditory processing issues

Difficulty finding words and understanding language



How to Help

Reminiscence Therapy

is the discussion of memories and experiences through the use of prompts, such as photographs, videos, or other sentimental objects. It can positively impact quality of life, mood and communication.

Enriching Activities

such as art, music, or other hobbies can help people to exercise their brain and connect with skills that are more deeply ingrained in muscle memory.

Intergenerational Therapy

is the process of getting different generations of people to engage with each other, whether by activities, hobbies, or just having a chat. These programs can improve wellbeing and mood in participants.

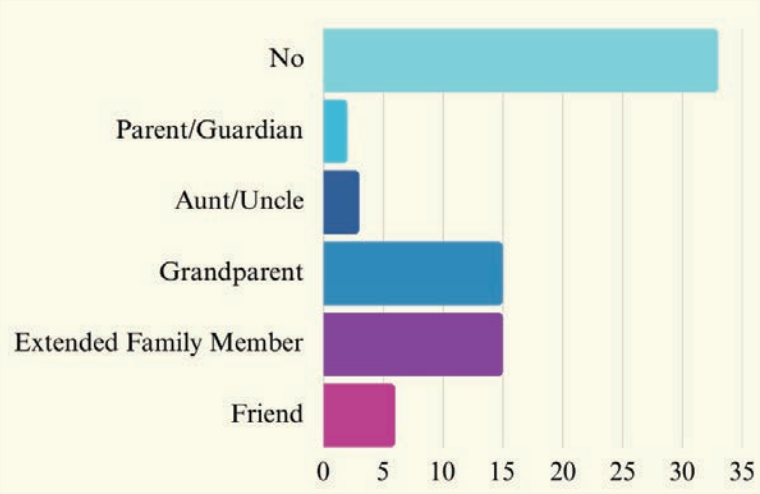
Human Interaction

is immensely helpful to those with Alzheimer's. Even a short conversation about the weather or what they are doing can help people stay grounded and help them feel seen.

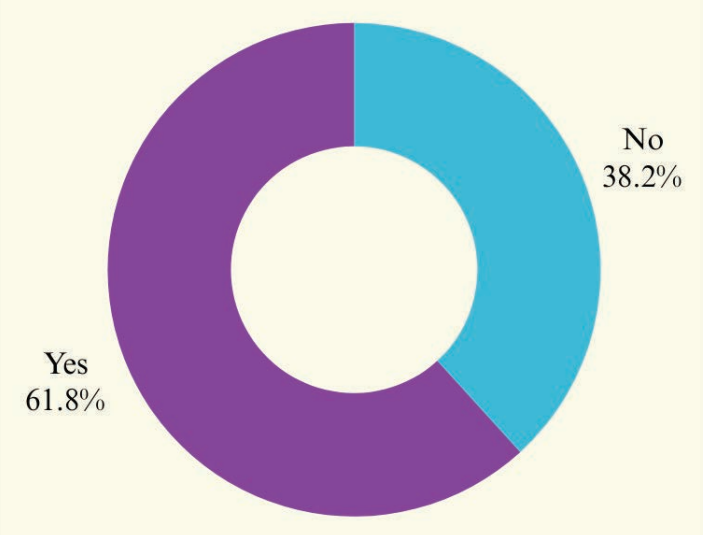
Public Conception of Alzheimer's

I anonymously surveyed 68 people on their preexisting knowledge of Alzheimer's.

To your knowledge, are there people in your life living with Alzheimer's?



Did you know that Alzheimer's can present as other symptoms besides memory loss?



First words or phrases that respondents associated with Alzheimer's Disease

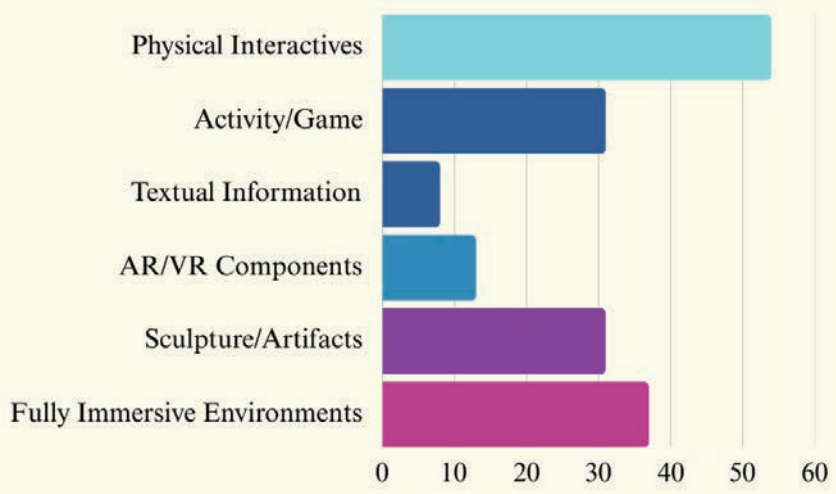
Most respondents were aged 18-24 with little personal connection to Alzheimer's and a broad, superficial understanding of the disease.

Evaluating Existing Alzheimer's Exhibits

Love Me, Hug Me is an immersive interactive exhibit telling the love story of the artist's grandparents and their struggle with her grandfather's Alzheimer's diagnosis later in life.

Town Square is an initiative to facilitate reminiscence therapy through an immersive model of a town from the 1950s, when visitors' memories are strongest. As an adult day care, it offers activities to engage visitors during the day.

At a museum, which of these exhibit types are you most drawn to?



In the same survey of 68 people, I asked respondents for their thoughts on exhibit engagement

Many successful and high profile Alzheimer's exhibits highlight themes of grief and fading memory. These premises, while wholly justified, come with a blind spot in the realm of education. Powerful connotations can dissuade uneducated or un-invested audiences from engaging in the topic. Additionally, large text was strongly off-putting to everyday viewers. They voiced a desire to process and interpret information themselves through discovery instead of being told facts or given a static narrative.

There is a need for neutral and approachable middle ground that engages those that are unfamiliar with a sense of play and a focus on interactivity.

APHASIA

is a full-scale, interactive diorama of a surrealist domestic scene from the 90s-2000s era. It is embedded with interactives that speak to universal sensory experiences, educating visitors on the intimate and often unseen reality of living with Alzheimer's. Breaking away from the graveness of grief and loss, it encourages a dialogue based in curiosity on how to celebrate and engage with the time we share in the present.

The goal was to create a space that encouraged curiosity, exploration, and discussion by meeting the audience in a space that reflected their own experiences. The young adult demographic was growing up in the turn of the century, and the media we consume pushes a narrative of nostalgia around this suburban domestic aesthetic, regardless of whether someone has truly lived it.

I wanted to explore feelings of familiarity, comfort, confusion, and wonder. I believe Alzheimer's should be represented by the everyday and mundane in order to create a more accessible discourse.

Key Interactives

Unsolvable Puzzle

A puzzle that gives an impression of a final image when disassembled, but does not match up at all.

Reappearing Dust

A projection of large, dark dust clouds within the space that can be cleared away with a broom, but that quickly re-accumulates regardless.

Landline Phone

A landline will ring and one side of a brief distorted conversation call can be heard.

Ambient Noises

Ambient and household noises will overlap throughout the space, occasionally cut through with a piano song.

Foggy Visor

Glasses modified to restrict viewing below oneself and peripheral vision. Visitors can experience the exhibit with these on.

Window Hallucinations

A back-lit print decorated like a window, showing the world outside with shadowy figures subtly dispersed.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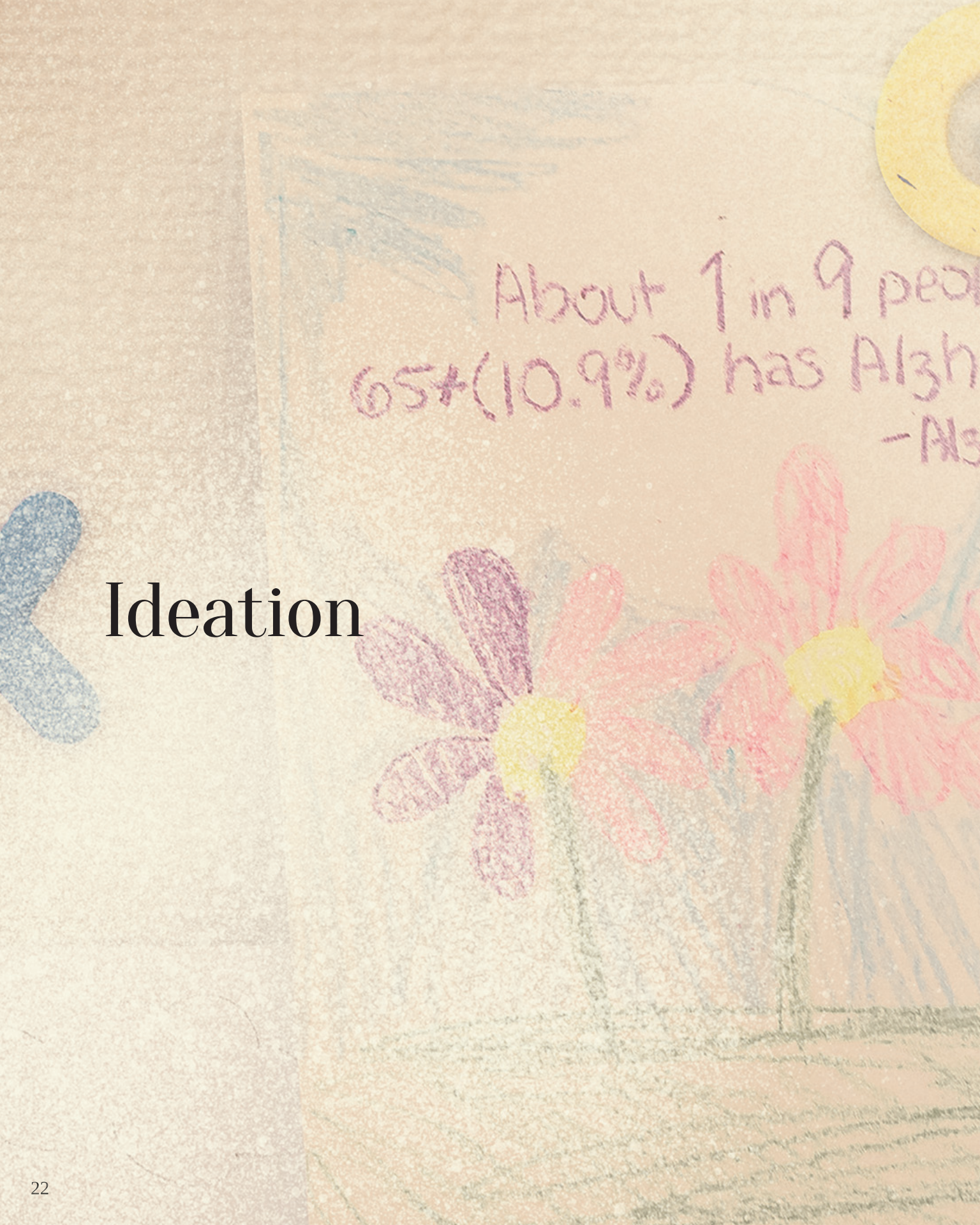

Ideation


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heimer's.
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Association

Aesthetic Refinement

Initially, I wanted to create a deeply uncanny scene inspired by the 1950-60s era that would most literally translate the evocative imagery of current Alzheimer's art and discussion.

Similar to the Town Square exhibit, it would have used immersive reminiscence therapy techniques to show visitors how memories can be powerful tools to ground and focus people.

But, after receiving feedback on the moodboards, I found that my target audience of young adults still felt alienated by the vintage imagery. They were still seeking a personal connection and relevance to the project and felt out of place in the original direction.

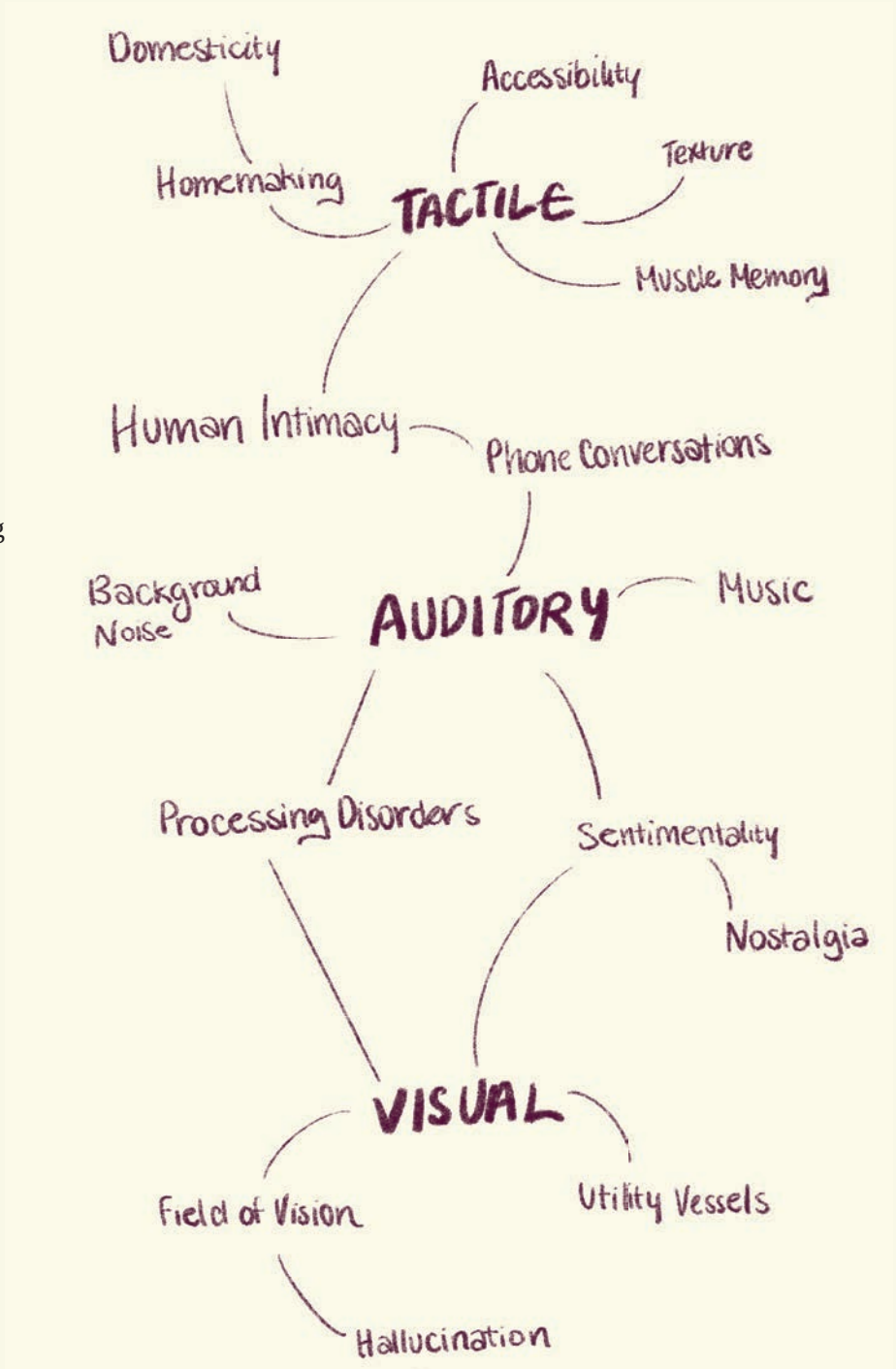
My updated approach still aimed to capture this sense of nostalgic “golden age”, but instead targeting the early childhood of a college student at the turn of the century. I aimed to put viewers in the shoes of a person experiencing reminiscence therapy, immersing them the intimately personal yet universally nostalgic zeitgeist of the Y2K era.

Interactive Ideation

I began with three basic senses that would be accessible to both those with Alzheimer's and without: Touch, hearing, and vision.

From my initial mind map, I brainstormed a list of ten different potential interactives I could disperse throughout the space that adhered to these categories.

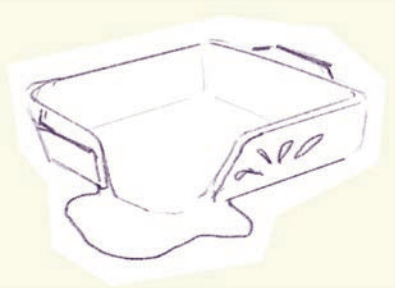
After rounds of prototyping and user testing, four of them were discontinued, for a final implementation of 6 interactives.



Failed Concepts

Ceramic Vessels
Description: Vintage-style ceramic vessels exist in the space, but have their topology heavily altered to become unusable.

Feedback: Responses were mixed, with confusion of the purpose voiced heavily. The lack of value led it to be discontinued.

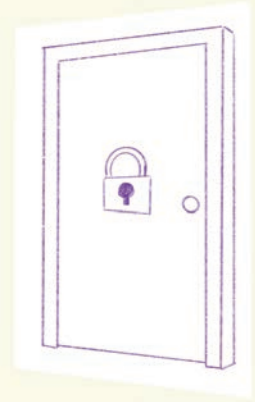


Embedded Objects
Description: Vintage, discontinued objects such as rotary phones will be embedded into the architecture of the space in unexpected ways to create a surreal, uncanny atmosphere.

Feedback: Responses were positive, but the lack of purpose left the interactive empty and not adding value. This was incorporated into the overall aesthetic of the exhibit instead of being implemented solo.

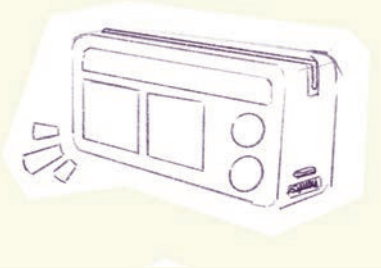
Door
Description: A freestanding home entry door that opens into the exhibit, making a doorbell noise, but that cannot be exited, forcing visitors to step around it to leave the space.

Feedback: Positive response with a variety of thematically appropriate interpretations of control, feeling trapped, caregiver/dependent dynamic, and memory. Ultimately too difficult to create and plan logistics for compared to the magnitude of its impact.



Contemporary Gadgets
Description: Highly modern tools will stick out in the space, seemingly high-tech but lacking an obvious use case.

Feedback: Proposed by a medical expert to mimic the struggle to navigate a modern world with increasing memory loss, but cut due to lack of time.



Successful Concept Prototyping

Six concepts went through several rounds of user testing, prototyping, and expert feedback to be implemented into the final exhibit.

Puzzle
Description: A puzzle that gives an impression of a final image when disassembled, but does not match up at all.

Feedback: Evokes frustration and confusion in people, but excitement at being able to fit the few pieces that do align. They typically lose interest after 2-5 minutes.

Initial testing focused on size and difficulty of the puzzle to find something that looked doable. The final interactive was laser cut in matboard.

Dust
Description: A projection of large, dark dust clouds within the space that can be cleared away with a broom or hand movements, but that quickly re-accumulates regardless.

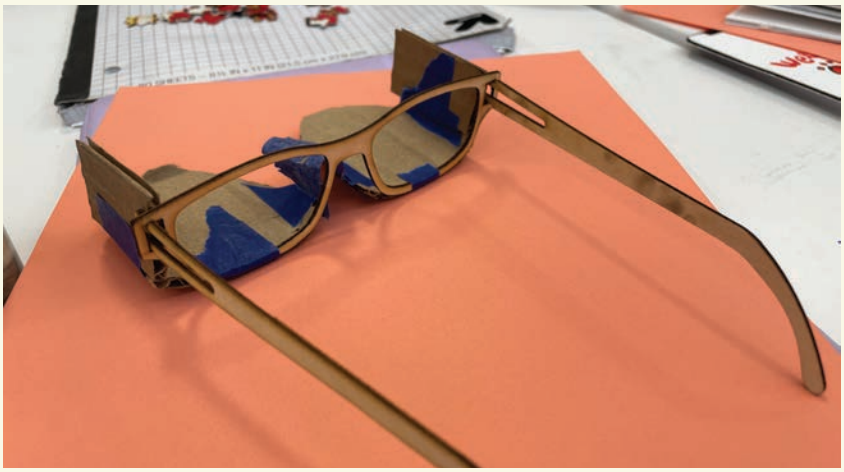
Feedback: Extremely positive feedback with clear interpretations of frustration, hallucination, and the cyclical, perpetual nature of the disease. May be difficult to implement.

This interactive was created in TouchDesigner, an interactive audio/ visual software. Input from a video device is translated into motion vectors that interact with a projected particle system,creating a real-time regenerative dust cloud. This was my first experience with the software, and taught me a lot about the flow of UX design.

Successful Concept Prototyping

Glasses
Description: Glasses modified to restrict viewing below oneself and peripheral vision. Visitors will experience the exhibit with these on.

Feedback: Initial cardboard model required more face contours, and the material was changed to frosted acrylic to mimic blurry vision. Testers reported feeling nervous and anxious about walking around, and not realizing how much vision was missing until they tried to walk.



Several cardboard iterations were tested to ensure the design was comfortable and fit most head sizes. The final material was laser cut acrylic bent with heat.

Window Figures
Description: A light pad decorated like a window, showing the world outside with shadowy figures barely visible.

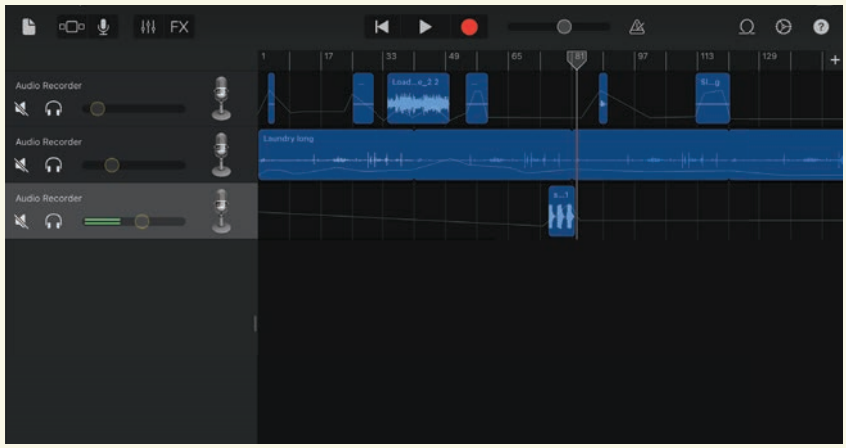
Feedback: Initial proposals included nighttime settings and people staring through the windows, evoking too much fear in testers. The switch to daytime and playful, distant figures was described as subtle, longing, and reminded people of fading memories.

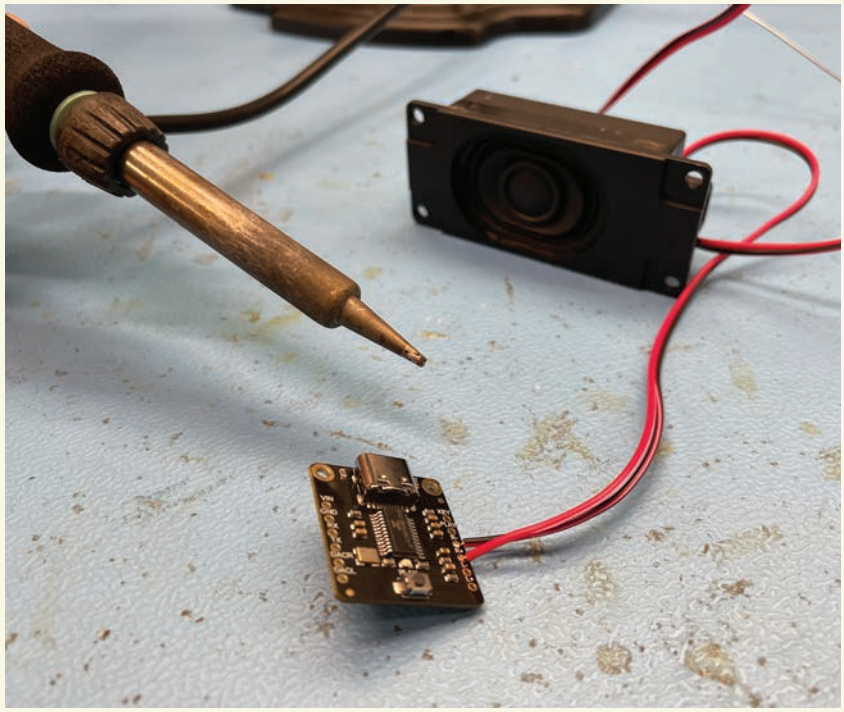
The idea began as a computer monitor playing a looping gif, but ended up as a light pad with a transparent film overlay. Different visual approaches were considered before landing on the garden.

Successful Concept Prototyping

Backing Track
Description: Ambient noises play overlapping constantly throughout the space at a volume just a little too high, occasionally cut through with only a calming song.

Feedback: Music can calm and center those with Alzheimer's, while ambient noises can often become overstimulating due to the brain failing to distinguish hierarchy of focus.

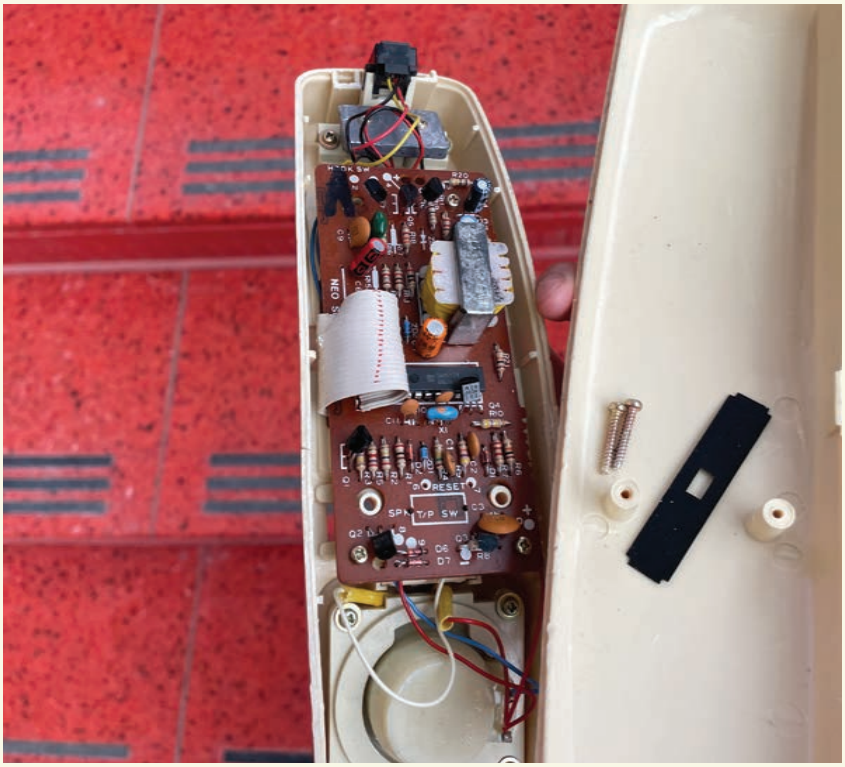


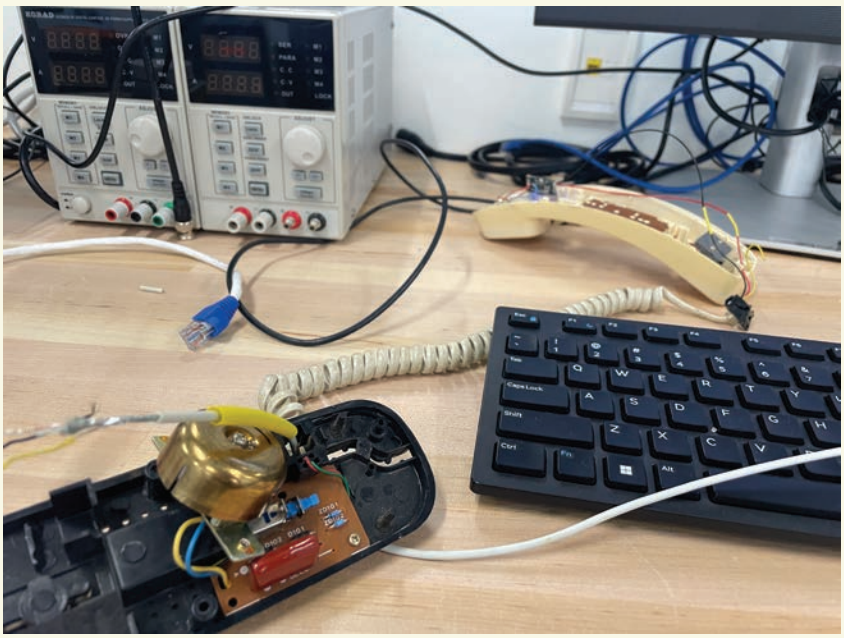


I created four different audio tracks using recordings from around my apartment overlaid within the GarageBand software. Using a specialized audio microcontroller called the DF Player Pro, I was able to insert a file into the microcontroller and solder a speaker to it for output. In total, 4 of these devices were created for the space.

Landline
Description: A landline will ring constantly until picked up, where a short, garbled, barely intelligible call can be heard.

Feedback: Received universal confusion and struggle to make out details, but was refined to be more purposeful by replacing background noise with “English-sounding” speech to mimic aphasia, and including clear dialogue alluding to family visits and expressions of love.

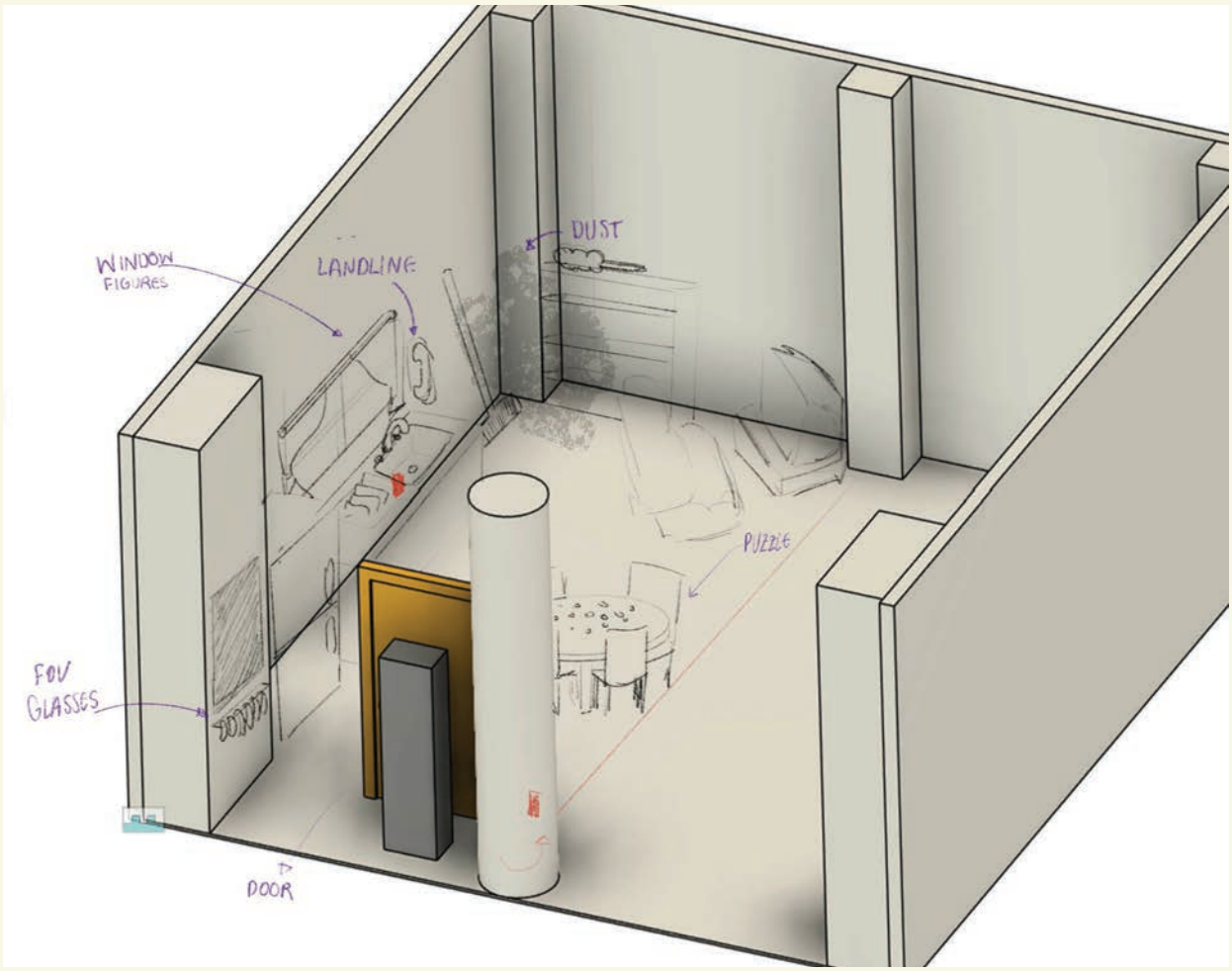




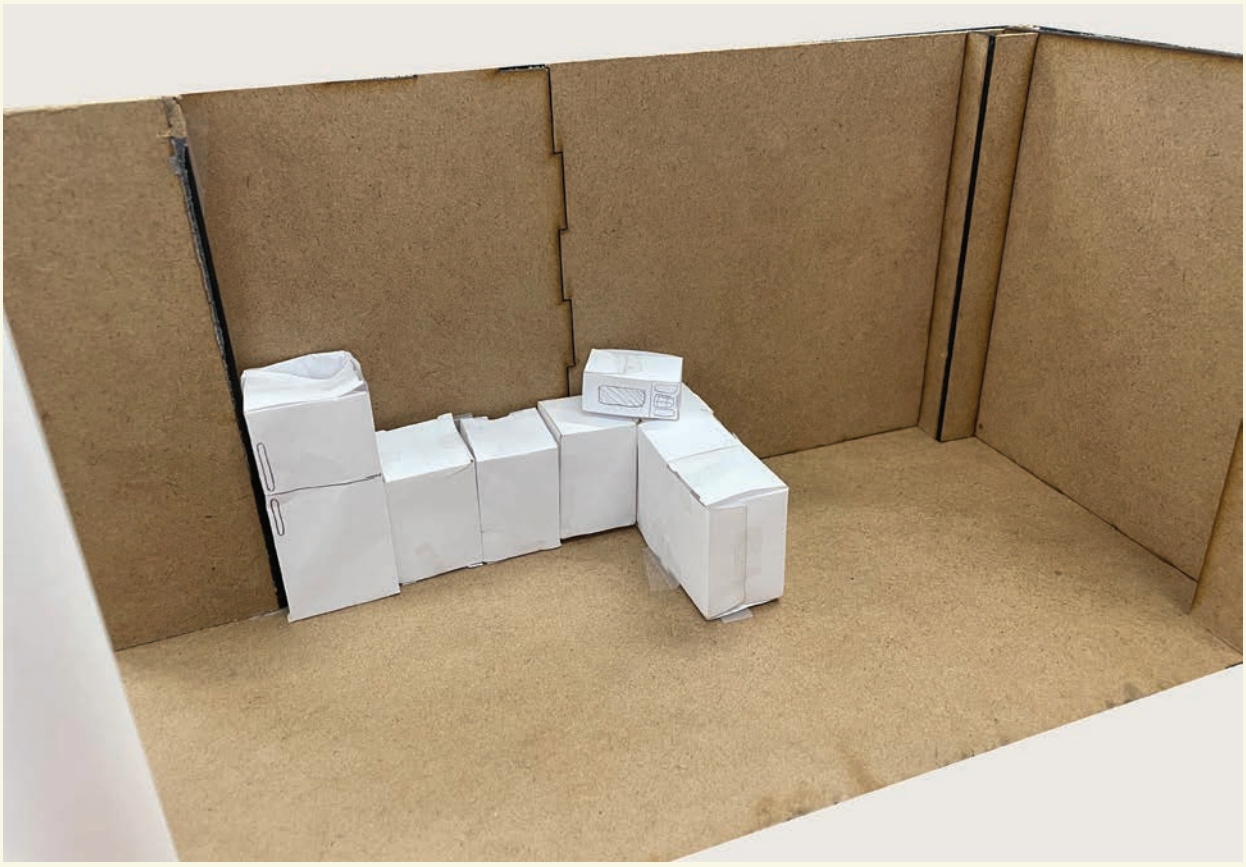
After sourcing a vintage phone, I disassembled the insides and replaced them with a DF Player Pro that I wired to the original cord input and speaker to maintain the hardware of the phone. I soldered a stripped lighting power cable to the base so it could receive USB power input. Finally, I added an on/off button to the interface for visitors to use.

Floor Plan Modeling

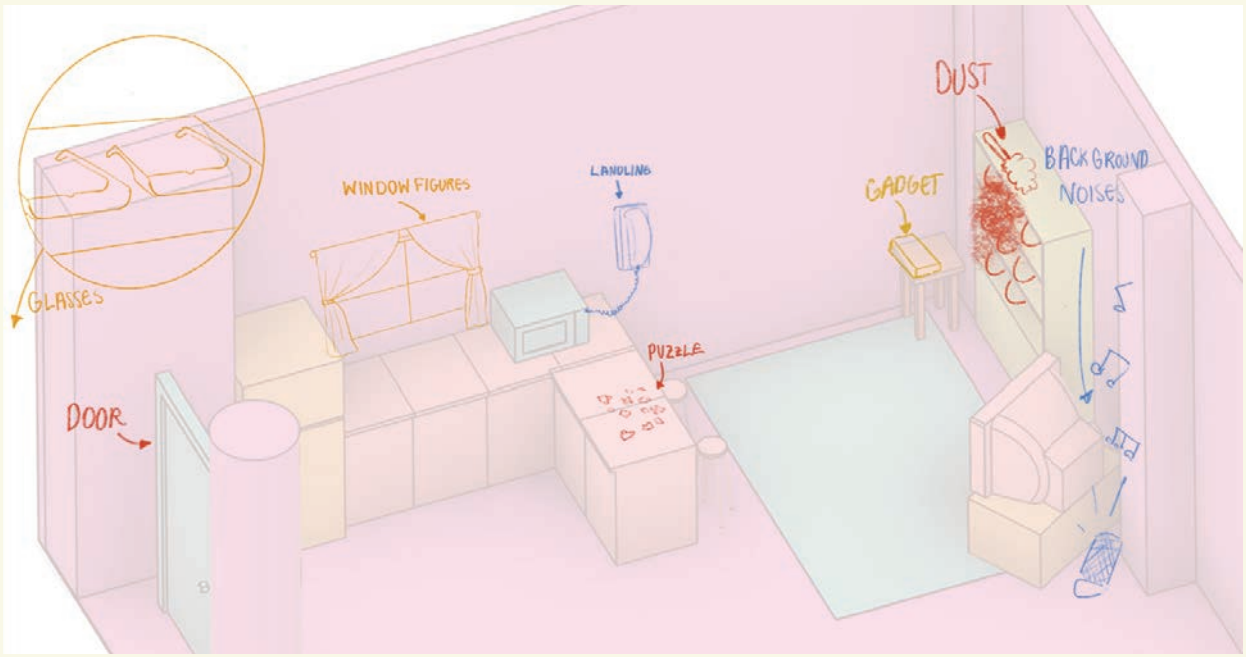
While creating interactive concepts, I measured and modeled the gallery space in Fusion 360 to begin mapping out the user journey. I then moved to paper mock-ups to decide the large structural elements I would use to define and anchor the exhibit as a recognizable domestic setting.



Initial sketching atop a Fusion model of the gallery space



Laser cut paper and MDF model



Refined CAD model to scale

Final Layout


6

Construction


IMPORTANT PHONE #'S

Construction

For cost, ease of transportation, and weight, I decided to create 3 pieces of set furniture to populate the space and define it as a kitchen.

I created the shells in Fusion 360 that referenced the standardized lumber I would use, but found that the real wood had more warping, cracking, and knots than I had anticipated. As someone inexperienced with wood, I had to make a lot of last minute adjustments and seek out help.

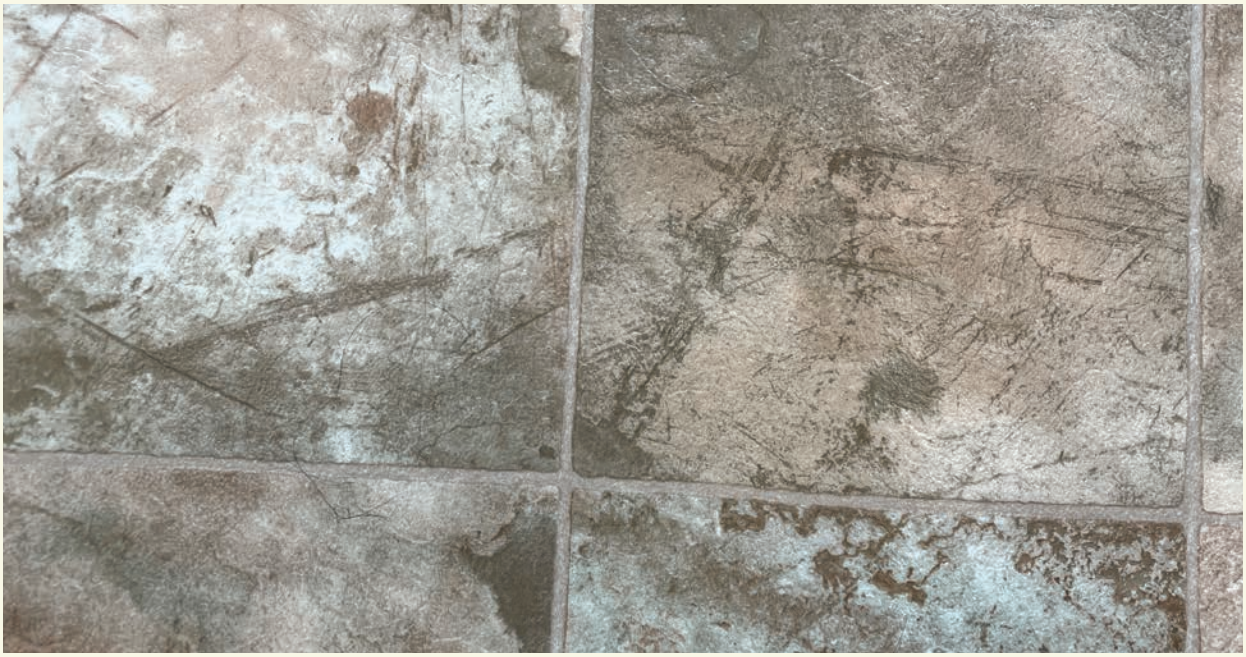
I used a brad nailer to join the frame and staples to attach the 1/8” plywood.

Internal support structure made from 2x2 lumber and recycled shipping crates

Construction

I quickly realized the need for proper alignment and quick-fix solutions as I began assembling the frame. I relied almost entirely on help from more experienced woodworkers to cut, square, nail, and glue the frames.

The wooden shells were covered in contact vinyl, a high coverage, high detail material that lent a cheap and dated feel to the pieces. I sourced vintage scrap flooring and wallpaper from a local thrift store, and weathered the vinyl with coffee and turmeric to feel more lived in.

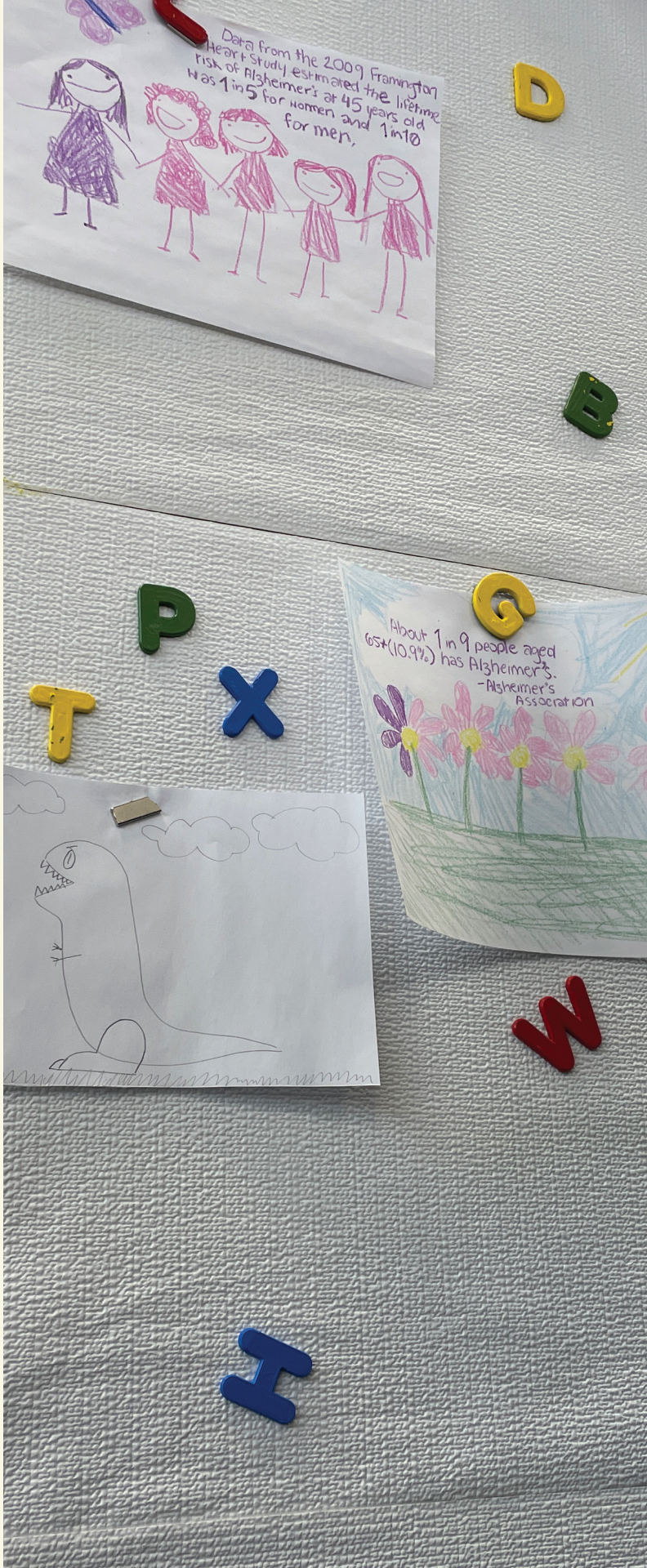


Detailing

Using a combination of 3D printing and secondhand items, I completed the structures with details that spoke to the surreal intentions of the exhibit.

Classically-colored letter magnets are arranged throughout the fridge, but the twelve most common letters do not appear, referencing the difficulty of language formation and use that is common in those with Alzheimer's. I arranged the handles without cabinet doors along a nonsensical grid, hoping catch a confused viewer's second glance or have people ponder why the kitchen feels "off". I also created a scrap book to live on a side table, filled with barely intelligible phrases and altered photographs aiming to visually represent the deterioration of memory in a physical way.

In essence, I wanted to populate the space with little details that encouraged and rewarded viewers for exploring and looking carefully.



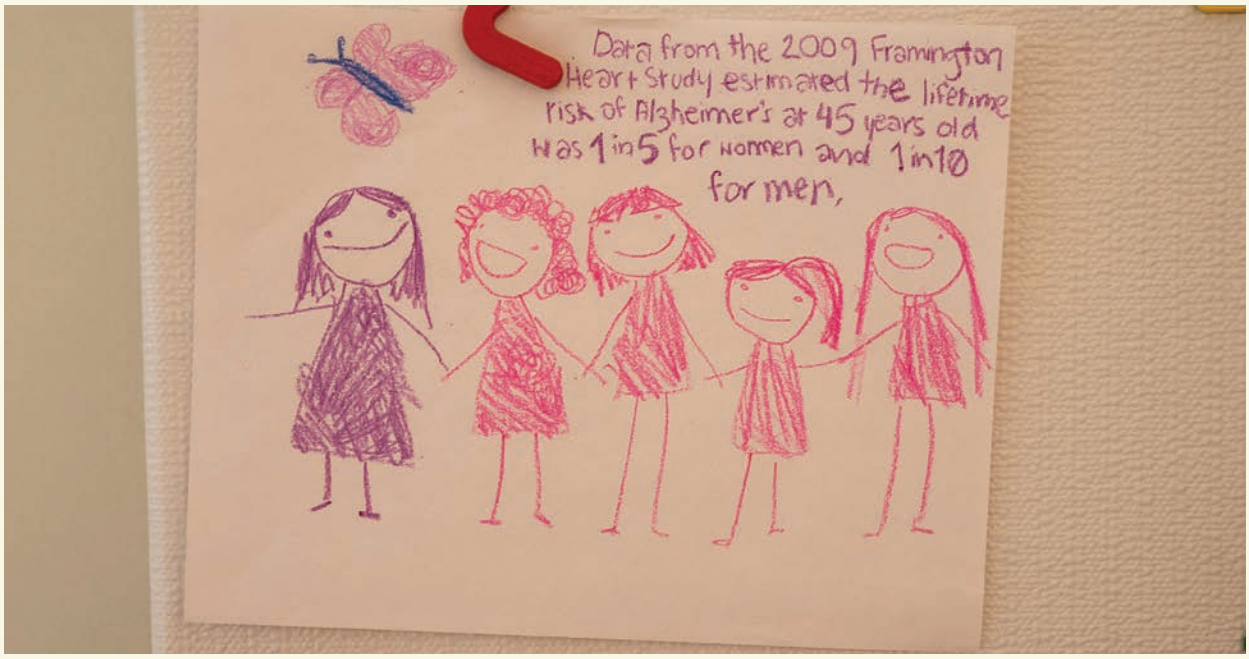
Glued drawer handles imply a sense of grid and direction, but lack their fundamental purpose and sense

Edited images populate the exhibit, ubtley jumbling faces and background details

Learning Outcomes

Across the exhibit are nine pieces of informational signage and reflection prompts that prompt the viewer to connect the material to their own life.

In my audience assessment, many respondents expressed desire to be engaged with by the material in a way that resonated personally. By incentivizing discovery and curiosity, I wanted to capture viewers in an open mindset that would prompt a deeper, earnest connection with the material and their own feelings.


Data from the 2009 Framington Heart Study estimated the lifetime risk of Alzheimer's at 45 years old was 1 in 5 for women and 1 in 10 for men.


For Food Safety and Quality
Nutrition Facts
Calories 470
While those with Alzheimer's don't often have issues with visual perception, higher level visuospatial skills impact object perception, interpretation, and depth perception.
How do the glasses change how you move around?
Popcorn Chicken
Kid Cuisine


IMPORTANT PHON
POLICE
911
FIRE
MOM
DAD
MYSELF


Reminiscence therapy is the discussion
of memories and experiences through
the use of prompts such as photographs,
videos, or other sentimental objects. It
can positively impact quality of life,
mood and communication
Which memories make
you feel happiest?


HONEY
CRUNCH
'N
OATS


HONEY
CRUNCH
OATS