Persona

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Abstract

Dementia shows us human existence without any decoration. We see it is heartbreaking, fragile, and delicate in all details. And we see more similarities than differences in our lives than we might imagine. We are all familiar with sadness, joy, fear, despair, depression, and happiness. People who have dementia feel the same way. Sadly, emotions confuse them and us.

Formal and informal caregivers play a major role in caring for people who have dementia. These caregivers, however, frequently face great strain from care, stress, and have an increased risk of depression and anxiety. Their psychological distress is mostly caused by the shifting nature of dementia and its complexity. Despite the growing global impact, a lack of understanding of dementia leads to fears and to stigmatization. For those living with dementia (both the person and their family), the stigma gives rise to social isolation and to delays in looking for diagnosis and help. Therefore, there is an urgent need to raise awareness and understanding of dementia in all strata of society as a move towards enhancing the quality of life of people who have dementia and their caregivers and to adequately prepare formal and informal caregivers.
'Persona' is an artistic research project that adopts multiple design strategies to convey a better understanding of dementia to (in)formal caregivers and the public. Centered around scientific studies, and insights from primary caregivers, specialists, designers, and in collaboration with artists, this project aims to create an immersive experience to cultivate empathy, improve competence and alleviate psychological distress, and in doing so, humanize the disease and embrace the fragility of the human mind.

The key research question that was part of, and resulted out of this process, is the following:

How can visual communication improve our understanding of dementia, and cultivate empathy?

The resulting design research, application, and evaluations will be published online in the Spring of 2021 as a resource for future exploration.

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1. Introduction

1.1. Professional motivation and personal motivation

1.1.1. Professional motivation

I would characterize myself as a socially aware visual designer and researcher with a multidisciplinary background. Academic and practical artistic education within the fields of visual arts and design has honed my understanding of the field of visual communication. My approach is grounded in research and insight, as well as experimentation and use of creative methodology. I acknowledge the field's social and ecological responsibility as I believe design will continue to shape our future and way of living. I am interested in rethinking and reimagining scenarios which alter our perception of the world and I believe we designers need to take our responsibility seriously and use our skills to create shared values that go beyond economic growth, and benefit society and the environment.

1.1.2. Personal motivation

My main motivation comes from a desire to better understand the world I live in, and to share and communicate that knowledge with others. I enjoy creative pursuits. With each new project, I am always trying to expand my skills as a designer and knowledge of a particular field. Naturally, this project is a unique opportunity to explore a topic of interest deeper than what is often possible later in professional practice. I have had a long-standing interest in science and the human mind. In particular, I am fascinated by life and human emotions; What makes us who we are? What is beyond us, beyond the realm of the everyday? How do we perceive the world around us and what shapes our understanding of it? What makes us unique in this vast world? What might shift our perspective? And how do we get affected by these experiences? These are the questions I keep coming back to and which I would explore deeper into the master's project. Clearly, this cycle of questions does not stop here, and there is a chaining effect that connects these to the other topics and fields.
With this project, I wanted to take the opportunity to do something outside the box and search for topics that would give me plenty of room for experimentation around such ideas. By working with immersive technology and visual communication design, it is therefore possible to explore my interests in sharing knowledge and using storytelling, in a context where this could have a positive impact on someone's life quality.

1.2. Social relevance

1.2.1. Rates of dementia

About 50 million people worldwide have dementia, with approximately 60 percent living in low-and middle-income countries. There are about 10 million new cases per year. The relative proportion of the general population aged 60 and over with dementia at a given time is somewhere between 5-8%. The overall number of people with dementia is estimated to hit 82 million by 2030 and 152 by 2050. A significant portion of this rise is due to the growing number of people with dementia living in low-and middle-income countries (Prince, 2015).

1.2.2. Dementia in Norway

Little direct information about the prevalence of dementia among the Norwegian population is available. Reports based on several Western European indicate an incidence of 6.9 per cent among people over 59 years (Prince et al., 2013). World Health Organization (WHO) statistics demonstrate that 7.3 per cent of people over 59 without an institution have dementia (Batsch, 2012). Through using data from research studies in other European countries, Alzheimer Europe found that dementia in Norway had a prevalence of just under 80,000 people in 2013. Perhaps this figure is too low since general life expectancy has increased and because life expectancy in Norway is somewhat higher than Europe and the rest of the West.
In addition, many people live with undiagnosed dementia. The rates of dementia in nursing homes and among people seeking home care is very well estimated in Norway. Over 80 percent of those who have long-term care in nursing homes, and over 40 percent of those aged over 70 who are given home care are diagnosed with dementia.

By combining these statistics, it is estimated that there are nearly 71,000 people with dementia among home care recipients and nursing home residents. Moreover, there are those who do not receive care at home or are in a nursing home. Nevertheless, this is only an example in Europe. Globally, the numbers of people living with dementia is much higher.

1.2.3. Social and economic impact

Dementia affects the people with the condition, who gradually lose their abilities, as well as their relatives and other caregivers, who have to cope with watching a family member or friend get ill and decline, while responding to their needs, such as dependency and behavioral changes. It also affects the wider society because people with dementia also need health and social care. The 2019 global cost of dementia was estimated at US$ 1trillion and will continue to grow as the number of people with dementia rises. Almost 85 percent of the costs are related to family and social care rather than medical care.

A recent Norwegian research on dementia from a sociological standpoint has examined resource use, estimated the total socioeconomic costs of dementia diseases, and measured the cost-efficiency of municipal services for dementia patients. It also estimated the expected need for resources related to dementia and assessed the possible need for services in the time ahead in socioeconomic terms. The study shows that a person with dementia has an estimated cost of NOK 360 000 a year for society (Røen et al., 2017). This means that the total costs could amount to almost NOK 30 billion a year.

1.2.4. Human rights

People who have dementia are often denied the fundamental rights and freedoms accessible to others. In many countries, physical and chemical controls are frequently used in care homes for older people and in intensive care facilities. Even where regulations are in place to uphold the people's rights to freedom and choice. An appropriate and inclusive legislative environment based on internationally accepted human rights principles is required to ensure the highest quality of care for people with dementia and their caregivers.

1.2.5. WHO response

WHO recognizes dementia as a public health priority. In May 2017, the World Health Assembly adopted the 2017-2025 Global Action Plan on the Reaction to Dementia in Public Health. The Strategy sets out a detailed action plan – for policy makers, foreign, regional, and national stakeholders, and the WHO, as in the following areas: treating dementia as a priority for public health; raising awareness of dementia and establishing dementia-friendly initiatives; reducing the risk of dementia; diagnosis, treatment and care; information systems for dementia; support for dementia care providers; and research and innovation. WHO has developed many platforms, in which they provide guidance and operationalized dementia plans. The Global Dementia Observatory, Towards a dementia plan: a WHO guide, Guidelines on risk reduction of cognitive decline and dementia, Mental Health Gap Action Programme (mhGAP), and iSupport to name a few (Cahill, 2020).

2. Methodology

Throughout the project, a variety of research methods were used to thoroughly examine the proposed research question. Literary research, including books, and articles remained the preliminary method for examining the nervous system and its function, human vision and hearing, learning and memory, the aging brain, and dementia. The objective information collected from each source spurred further research that required interviews and conversations with experts in relevant fields. These expert interviews included caregivers who had extensive experience with people with dementia, healthcare professionals and specialists. Once the essential foundation for scientific research had been gathered, a series of experimental studies were completed to assess the theories conceived throughout the research phase.

These experiments included the idea development, mock-ups, and prototypes for the final experience. By conceiving the research from a design perspective, the project integrated a spirit of exploration and curiosity, which allowed room for failure and the opportunity for the project to continuously evolve. In combination with scientific research, case studies in dementia design intervention and immersive technologies contributed to the production of the project. The critical design practices applied in these phases allowed me to build a perceptual bridge between the audience and the context. Instead of using design merely as a tool for problem solving, I tried to revitalize the desire for knowledge and raise awareness through the use of emotional narratives and storytelling.

3. Theory

3.1. The nervous system and its function

Throughout our lives, we form pathways within the brain composed of millions of nerve cells. As we mature, these networks increase in complexity, a process similar to a tree's branching as it grows. Our mental skills evolve as an accompaniment to this anatomical and functional brain complexity as well. Nevertheless, the most inspiring of insights about the brain is that we can improve our brain's performance by our own efforts. Therefore, learning about the brain provides a wonderful mix of guidance, amazement, and self-improvement. As you gain knowledge, you're in a better position to improve its functioning and thereby increase the quality of your life.

Whether it be a surprise, a startle, or a scare, how the brain reacts to a situation is determined by the information that is gathered by the nervous system. The nervous system, including the brain, is made up of billions of interlinked neurons (Figure 1). Through this vast interconnected web, the brain can gather information, interpret them, and then react to them in a matter of milliseconds governing such things like how hard we laugh, how loud we scream, or how fast our heart races. The nervous system regulates every reaction, thought, action and emotion which excels in communication and control.

In harmony:
Think of the brain as an orchestral symphony. When everything goes right, the brain remains in constant communication with the whole body. Sometimes the signals are muted or lack direction when the musicians are warming up or the mind's attention is unfocused. But when the conductor walks to the podium and taps the baton, all snap to attention. Then everybody comes into action with the downsweep of the master's arms. Each musician watches for instructions, just like every nerve that records and transmits information. Upon recognizing the conductor's intent, each carries out orders to accelerate or slow down, emphasize or downplay a particular action, or otherwise fine-tune the adjustments that create music out of a hundred different sounds-or brain thoughts into physical action. The conductor, like the brain's executive function, also monitors the incoming signals. Each musician's performance impresses the maestro, who processes the information and calls for necessary modifications. As the musicians play together, their contributions become harmonious (Figure 2). Thus, the brain has its multitude of functions that, when combined, lead not only to consciousness, but also to overall health.

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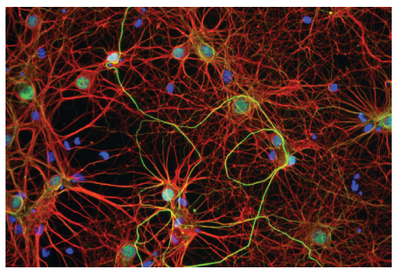

| 1 | Photo courtesy of GE Healthcare. Retrieved from http://www.flickr.com/photos/gehealthcare/4253587827/

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| 2 | Photo courtesy of Barry Blackman. Getty Images

The complexity of the brain and how it collects data and reacts to them lies in the very integration of its many neurons. Neural integration not only results in the interaction of sensations associated with motor activity, but also affects the way humans recall, perceive, and create.

Tim Berners-Lee likens the complexity of the brain to the near-infinite capacity for websites to connect to each other. *"A piece of information is really defined only by what it's related to"* he said. *"The structure is everything. There are billions of neurons in our brains, but what are neurons? Just cells. The brain has no knowledge until connections are made between neurons. All that we know, all that we are, comes from the way our neurons are connected."*

Occasionally, only one neuron excites another neuron, and so on, like a single row of toppling dominoes. The result of such is a clear-cut response. Other times, sensory information extends into several routes. A single neuron may excite a few others, like one that sets a dozen rows in motion. This triggers *"parallel processing"* of information as circuits diverge and converge in the central nervous system. At the same time, each neural circuit delivers different information. The stimuli are unique, not only among every human, but also from instance to instance in a single brain, thanks to the addition of new experiences and environments (Silverthorn, 2018).

3.2. Vision and hearing

Consider your sense of sight. As you read this sentence, your brain's visual networks are taking in more than 100 million pieces of information. Your eyes constantly move from one place to another, usually never landing longer than a split second on any single word. Peripheral vision outside of the dimensions of this page is a blur of color and shape; only a tiny area in the center of the eye called the fovea contains enough photoreceptors to see with great sharpness. You may think you see the entire world as a sharp and seamless whole, but your retinas are separating information into different categories, such as color, shape, and line, and allowing acuity only on a small spot in the center of your field of vision. This screening process prevents the brain from being overwhelmed by too much visual stimuli. Instead, it captures what the brain needs to create a useful image of the world as you shift your attention.

The sensory input received by the retina is passed through the thalamus to the corresponding areas of the visual cortex, which is located in the occipital lobe at the back of the brain. As you perceive an object's attributes, whether it's a word on a page or a bird flying up in the sky, your brain synthesizes the streams of information, pairs them with memory-saved images, and makes the association. Then, you recognize what you see. Because you reach these conclusions based on sketchy details, your brain fills in the blanks of perception.

Next to sight, hearing is one of the senses often regarded as most significant. The brain receives vital information about the environment through the noises and sounds around it. Sound is created by pressure fluctuations in a conducting medium, such as air. The brain registers sound when pressure

activates the auditory region of the temporal lobe of the cerebral cortex. When the auditory stimuli enter the brain stem, neural networks sort them out by tone and quality. The brain stem simplifies comprehension by eliminating those echoes commonly produced by vibrations that bounce off walls, ceilings, and floors. For example, if a sound is new or strange, through a potential threat, the brain stem lets it through. The brain stem also begins the processing of phonemes to facilitate speech comprehension. Like the brain's visual processing network, which separates and then synthesizes visual features, the auditory region of the temporal cortex contains neurons performing small, specific functions. While some neurons fire at the start of tone, others fire at the end. Some fire fairly easily, and others resist firing (Sweeney, 2009). In addition to the role in hearing, the ears contain structures essential to keeping the body upright and even, a property best known as balance. The lower brain stems of all vertebrates also function to maintain balance and a sense of spatial orientation. Balance is an incredible state of body equilibrium. It keeps the printed type steady in your visual field if you move your head from side to side. Unpleasant conditions occur when equilibrium breaks down (Sweeney, 2009).

3.3. Learning and memory

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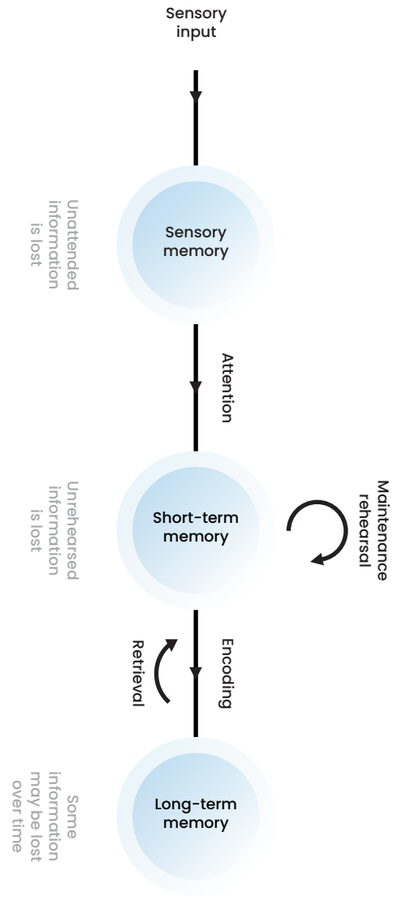

Learning and memory make each human unique. Even before birth, the human brain takes in sensations, processes them, and starts to encode them into trillions of synapses. Those connections, and the electrochemical firing patterns uniting these links differentiate the brain from what it was a moment before. As new connections are formed in response to stimuli, and then become strong through repeated use, the brain integrates new information and stores it until it is needed. The human brain would be little more than clockwork without learning and memory. Learning involves cognitive components, such as solving quadratic equations; motor components, such as tying a necktie; and affective components, such as feeling embarrassed in a social situation.

Memory is the ability to store and recall information. Memory has multiple storage levels, and our memory bank is constantly changing (Figure 3). When a stimulus comes into the CNS, it first goes into short-term memory, a limited storage space that can hold only about 7 to 12 pieces of information at a time. Items in short-term memory disappear unless an attempt, such as repetition, is made to put them into a more lasting form. Long-term memory is a storage area which can hold vast amounts of information. The processing of information that turns short-term memory into long-term memory is known as consolidation. Consolidation may take different periods of time, from seconds to minutes. During consolidation, information goes through many intermediate levels of memory, and in each of these stages, the information can be located and recalled.

| 3 | Adapted from Atkinson, R. C., & Shiffrin, R. M. (1968). *Human memory: A proposed system and its control processes.* In K. Spence (Ed.) The psychology of learning and motivation (Vol. 2). Oxford, England: Academic Press.

When we recall a memory, we call upon many of the very same neural pathways that sensed the event. Recall almost recreates the event, as evidenced by the warm, fuzzy feelings that come from a good kiss and the memory of a good kiss. In fact, the brain collects the information by firing a network that connects color, sound, emotion, spatial orientation, any other facts stored with the memory, and an overall network that integrates all the information (Sweeney, 2009).

Memory is also an individual thing. We process information based on our experiences and worldview. Because people have widely different experiences throughout their lives, it follows that no two people will process a given piece of information in the same way. If you ask a group of people about what happened during a particular event, such as a lecture or a car accident, no two descriptions will be identical. Each person processed the event according to his or her own perceptions and experiences (Silverthorn, 2018). Learning and memory work together. Some learning is turned into lasting memories; other experiences are ephemeral. Eric R. Kandel, recipient of the Nobel Prize for research on the molecular foundations of memory, draws this distinction: *"Learning is how you acquire new information about the world, and memory is how you store that information over time."* (Squire & Kandel, 2000)

3.4. The aging brain

The elderly brain loses an edge in some functions but generally stays active and even gains a little bit in others. Some neurons die due to normal aging or through disease or injury. Thanks to plasticity, however, a healthy elderly brain can actively redesign itself to respond to a reduction in neurotransmitters and loss of some neurons. Connections among neurons get pruned, leaving the most useful ones. The only cost is the brain's ability to quickly come up with information. Some areas of mental ability actually improve with age. The elderly brain enjoys a larger vocabulary and sharpened linguistic skills in the absence of disease. It also needs a higher concentration to retain and interpret sensory input, but the effect can be a focus on the essential stimuli and disregard for the peripheral.

With age, there is an overall decrease in brain volume, with the majority of gray matter shrinking occurring in the hippocampus and prefrontal cortex (PFC) (Anderton, 2002). Neuroinflammation is also present in aging brains (Barrientos et al., 2015). The cognitive changes associated with aging may be associated with minor changes in synaptic physiology of the hippocampus and PFC (Morrison & Baxter, 2012). This can lead to reduction of dendritic branching and spine counts in PFC neurons. Minor cognitive changes are common during normal aging. The most common functions with aging are declines in working memory (Stanley et al., 2015) and executive function (Kirova et al., 2015). Spatial memory also commonly worsens during normal aging and is likely due to hippocampus shrinkage and surrounding entorhinal cortex (Coughlan et al., 2018). Although less common, some additional changes in processing speed and attention may be observed (Harada et al., 2013).

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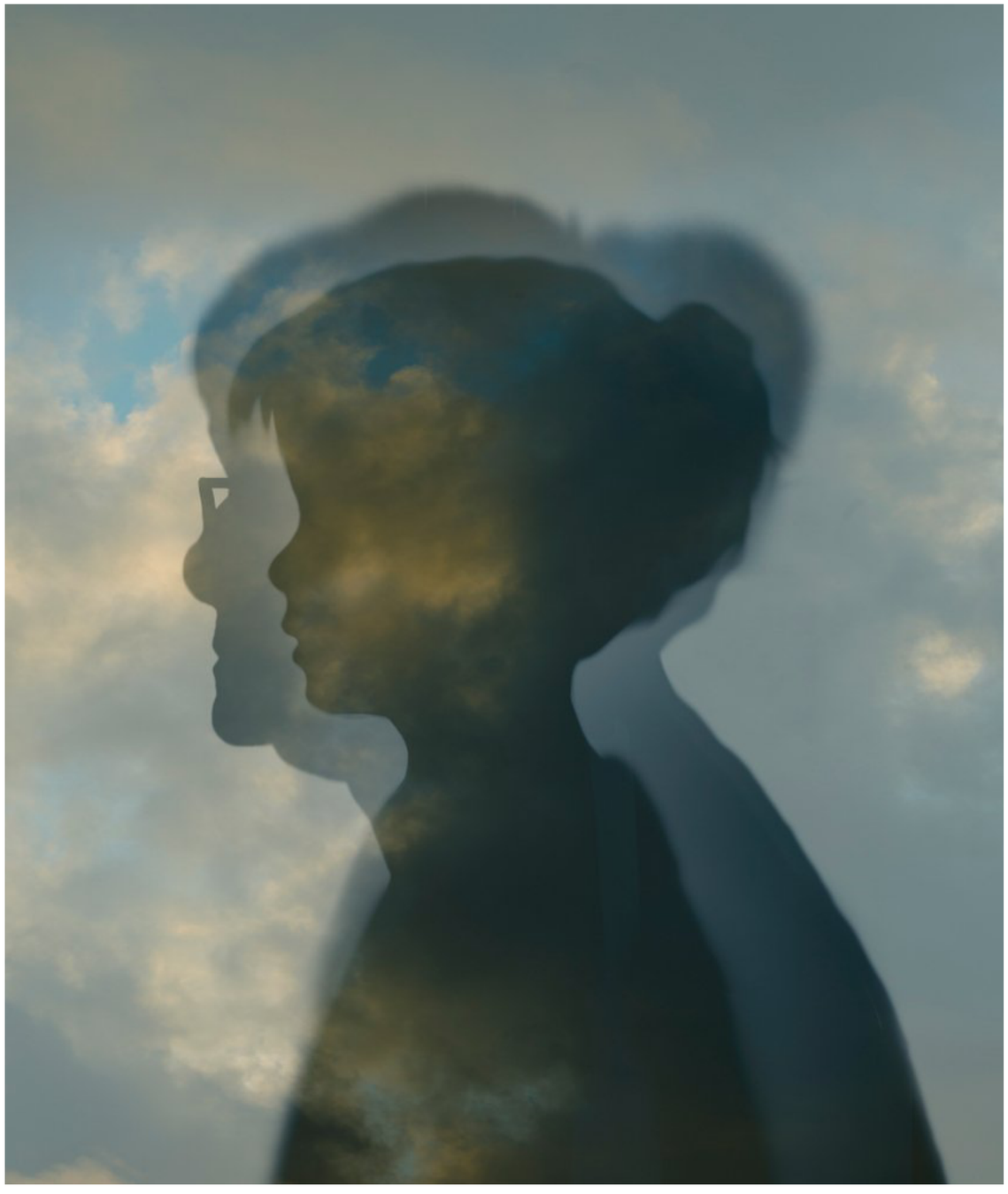

| 4 | Photo courtesy of Fanatic Studio, Science Photo Library (2019). *Aging* Retrieved from https://fineartamerica.com/featured/ageing-fanatic-studioscience-photo-library.html

Decision making and reasoning problems are common in older age as well and are linked to a decline in cardiovascular function. Importantly, these alterations in brain function do not warrant the diagnostic criteria for dementia. Declines in spatial memory and navigation occur during normal aging due to the impact of age on the hippocampus and can serve as an easily quantifiable indicator of HC functioning, as well as having relevance for conditions like Alzheimer's Disease.

Aging (Figure 4), affects various types of memory disparately, with working, associative, contextual, and spatial memory impaired in older adults (Craik, 2016). While more common visual functions such as distance and object perception are maintained, the elderly show impairments in vestibular processing, perception of self-motion and severe deficits in path integration (Harris & Wolbers, 2012). These affect the components of allocentric processing and lead to poorer spatial navigation performance. In addition, older adults experience greater difficulties in encoding and retrieving spatial information in long-term memory in large-scale settings that require exploration to be fully understood. A host of disorders and illnesses can affect the aging brain, from vision and hearing impairment to dementia.

3.5. Dementia

Dementia is generally characterized as a progressive neurodegenerative disorder, affecting a range of cognitive domains (Dening & Sandilyan, 2015) and impairing function. Dementia is associated with deterioration of memory, perception, learning, comprehension, decision making and behavior. By definition, dementia causes a loss of the ability to perform everyday tasks. Dementia has many different forms. The most prevalent type is Alzheimer's disease which may contribute to 60–70 percent of cases. Other major variations include vascular dementia, Lewy body dementia and a group of diseases that lead to frontotemporal dementia. The distinctions between various types of dementia are frequently indefinite, and mixed types often coexist.

3.5.1. Alzheimer's disease

Alzheimer's disease (AD) is defined by a progressive decline in cognitive function. AD is significantly increased among people aged 65 years or more, with a gradual deterioration in memory, thinking, language and learning capacity. AD should be differentiated from the normal age-related deterioration in cognitive function, which is more progressive and associated with less disability. Disease frequently starts with mild symptoms and ends with serious brain damage. People with dementia lose their abilities at different levels (Gross et al., 2012). The brain of Alzheimer's patients shows telltale signs. Alzheimer's sufferers lose about 10 percent to 15 percent of their mass, though it is common for the brain to slightly shrink as it ages. They also lose many more neurons than would be accounted for in normal aging, including up to 25 percent in certain cortical regions.

Alzheimer's patients also show vastly more neuronal damage in the hippocampus, crucial to memory formation, than would be expected from normal aging (Braak & Del Tredici, 2012).

3.5.2. Vascular dementia

Vascular dementia is the second most common type of dementia, which affects 20 percent of the cases. The major risk factor for vascular dementia is age. In fact, most people with the condition are over the age of 65. If the oxygen supply to the brain is reduced due to narrowing or blockage of blood vessels, some brain cells become damaged or die. Without enough blood, brain cells can't get sufficient amounts of oxygen and eventually die. The symptoms can happen unexpectedly after a major stroke. Or they can evolve over time, due to a series of small strokes. Vascular dementia can also be caused by a disease that affects the small blood vessels deep in the brain, known as subcortical vascular dementia. The symptoms of vascular dementia differ and may overlap with those of Alzheimer's disease. Many people have difficulties with problem-solving or planning, thinking quickly and focusing. They may also have short periods when they get really confused. Some people may feel anxious or become distant or depressed. They may also become more emotional and experience mood swings (Thal et al., 2012).

3.5.3. dementia with Lewy bodies

Dementia with Lewy bodies is caused by small circular clumps of protein that build up within nerve cells in the brain. One of these proteins is called alpha-synuclein, and the clumps are called Lewy bodies. Lewy bodies damage the nerve cells and impair the way they communicate. In DLB, the nerve cells that are impaired by Lewy bodies are in parts of the brain that control thinking, memory, and movement.

DLB is characterized by gradual cognitive and functional decline with at least two of the following additional symptoms: (1) prominent visual hallucinations; (2) fluctuations in concentration and alertness; (3) parkinsonian motor symptoms (McKeith et al., 2017). Usually, the hallucinations are visual, although auditory hallucinations have been described. The hallucinations seen early in the disease, remaining persistent throughout its course, are often detailed and vivid (McKeith, 2007). The emergence of such hallucinations is related to visuospatial perceptual deficits in these patients. The presence of visual hallucinations strongly differentiates DLB from AD, especially in the early stages of the disease. Trouble in remembering recent events is often an early, prominent symptom of Alzheimer's disease. However, in DLB, memory is often good at an early stage of the illness. Instead, there could be uncertainty, mental slowness, trouble with spatial relations, visual and problem-solving difficulties (Ballard et al., 1999).

3.5.4. Hearing and vision impairment

Recent studies have found a link between hearing loss and dementia in elderly populations. Uhlmann et al. found a correlation between hearing impairment and dementia in a case–control study, the severity of hearing impairment was related to the relative odds of dementia incidence (Uhlmann et al., 1989). In addition, a prospective cohort study has shown that central auditory dysfunction may precede the onset of dementia for many years and could be used as an early risk marker for dementia (Gates et al., 1996).

Lin et al. have confirmed the link between hearing impairment and dementia in a prospective cohort study. They have concluded that future study needs to explain whether hearing loss is an early stage of dementia or a modifiable factor that can alter the risk of developing dementia (Lin, Metter, et al., 2011). In a cross-sectional cohort, Lin et al. found that a hearing loss of 25dB associated with cognitive loss equivalent to an additional 6.8 years of age (Lin, Ferrucci, et al., 2011). Cohort studies in Japanese and Italian elderly populations have shown a correlation between auditory function and results in MMSE score, indicating that hearing impairment is associated with cognitive dysfunction (Naramura et al., 1999).

Different forms of visual impairment have been observed in people with dementia; however, it is not yet clear whether visual impairment precedes the development of dementia and whether it could be used as an early marker for dementia risk. A wealth of evidence has demonstrated that the elderly with visual impairment perform worse on the conventional cognitive tests, and alternative forms for visually impaired patients should be used (Fridlich et al., 2009). Uhlmann et al. have found

that visual impairment is linked with increased risk for developing AD and increased severity of AD, however they could not establish a dose–response relationship (Uhlmann et al., 1991). With respect to different forms of visual impairment in dementia, contrast sensitivity has been found to be altered in AD patients when compared with age-matched controls (Lakshminarayanan et al., 1996). Furthermore, Rizzo et al. found that contrast sensitivity is compromised in AD patients, they found that visual attention, color, shape-from-motion, visuospatial construction and visual memory were also impaired in AD patients (Rizzo et al., 2000).

3.5.5. Hallucinations

A hallucination is an experience of something that is not actually present. They can occur in all the senses, though visual hallucinations (seeing things that are not really there) are the most common form experienced by people who have dementia. Visual hallucinations can be simple (e.g. seeing flashing lights) or complex (e.g. seeing animals, humans, or strange situations). Less commonly in people who have dementia, hallucinations can include hearing, smelling, tasting, or feeling things that do not really exist. These experiences might differ in degree of complexity, ranging from visual distortions to feelings of presence, passage hallucinations and complex delusions. VH can be found in different neurological and psychiatric conditions and are generally found in Dementia with Lewy Bodies (DLB) and Parkinson's Disease Dementia (PDD) (Waters & Fernyhough, 2017).

Complex VHs frequently occur in DLB and, together with parkinsonian features, cognitive fluctuations and REM sleep behavior disorder, represent the core clinical features for diagnosis (McKeith et al., 2017). In DLB, the hallucinatory experiences usually last minutes on a daily basis, they are typically stable and blurred and sometimes can persist with closed eyes (Mosimann et al., 2006).

How common is hearing and vision impairment in people who have dementia?

It is very common; Almost 90 percent of people with mild or moderate dementia experience significant hearing loss (Allen et al., 2003) and more than 30 percent have vision impairment (visual acuity less than 6/12). Hearing and vision deficiency are much more prevalent in people living in residential care homes (i.e., assisted living or nursing homes) (Bowen et al., 2016).

What is the impact of hearing and vision impairment in people who have dementia?

Dementia and hearing loss are both independent risk factors for delirium and their impacts are likely to interact, particularly in noisy environments such as acute hospitals. Hearing loss increases the likelihood of all types of psychotic symptoms and hallucinations in dementia also occur more frequently in people with visual and auditory impairments. Both hearing loss and dementia may cause social isolation and impairments in communication, functioning, participation in activities (Hubbard et al., 2018). Sensory impairments among nursing home residents have been associated with low social engagement and low time spent in activities (Resnick et al., 1997).

These characteristics may in turn be associated with low mood and depression, and the evidence indicates a link between lack of social participation and behavioral symptoms of dementia such as agitation and aggression (Cohen-Mansfield et al., 2012). A range of psychological and behavioral symptoms of dementia, such as depression, agitation, and aggression, can be intensified by untreated hearing loss in people with dementia.

People who have dementia and have hearing and/or vision impairment often experience a poorer quality of life and are frequently isolated. They may have more challenging behaviors (i.e., anxiety, agitation, aggression, or visual hallucinations), difficulties in adapting to environments (i.e., getting lost), and may become more dependent on caregivers. The symptoms of dementia may progress faster as well (Dawes et al., 2019). These overlapping effects and everchanging nature of the disease confuse the caregivers and cause caregiver burnout.

3.5.6. Caregiver strain

Those who are involved in providing services for people who have dementia frequently speak of a second patient in the making (the family caregiver) once a person is diagnosed with dementia (O'Brien et al., 2017). That means it is crucial to give equal priority to the needs of the primary caregiver who is a vital resource in the long-term care arrangements for people who have dementia. Caregivers face several roles that develop throughout the disease stages. Usually, the level of support increases as the disease progresses, beginning with support for everyday life tasks and expanding to personal treatment and eventually almost constant supervision. The types of treatment provided, the extent of each, and their progression over time, depend on many variables such as the clinical profile (forms and severity of cognitive impairments and behavioral and psychological symptoms, which may differ by subtype of dementia), the presence of comorbid physical and psychological complications, the habits of the individual who have dementia, and the person's personality. These caregivers often face great pressure from care, feel stressed, and have an increased risk of depression and anxiety (Sörensen & Conwell, 2011; Cooper et al., 2007; Pinquart & Sörensen, 2006). Therefore, the WHO has stressed the importance of finding solutions to improve the awareness and understanding of dementia in all walks of life as a step towards enhancing the quality of life of people who have dementia and their caregivers (Prince, 2013).

Caregivers' psychological distress is primarily caused by the changing nature of dementia (Borsje et al., 2016). Behavioral changes can be unpredictable to the caregivers in their nature, intensity, and timing, often turning the patient into a person who seems

rather different from the one that the caregiver has known. These behavioral changes include loss of intimacy in the relationship (Fauth et al., 2012), social isolation (Roth et al., 2005), less time for other non-care activities (Pearlin et al., 1990), and a lack of awareness of the changing behaviors. Few caregivers have any training on how to cope with the altered behaviors, and therefore struggle to provide care in the midst of changes occurring in their daily lives. Multiple studies have highlighted that caregivers should learn more about the symptoms and shifting behaviors associated with the disease (Van der Roest et al., 2009), as this may improve competence and alleviate psychological distress (Boots et al., 2014).

To alleviate these distresses, a potentially promising line of development is the creation of dementia simulation using VR technology, mostly developed in consultation with people who have dementia and their caregivers (Gilmartin-Thomas et al., 2018; Wijma et al., 2018; Adefila et al., 2016; Alzheimer's Research UK, 2016). Wearing a VR headset, individuals can take the first-person view of a person who has dementia and explore a virtual environment that moves around with their real-time movements. Within the virtual world, visual stimuli create typical dementia-like symptoms such as visual misperceptions, recognition problems and memory difficulties, e.g. colors and distances are warped and distorted; a stranger momentarily appears like a familiar person (Gilmartin-Thomas et al., 2018; Adefila et al., 2016; Alzheimer's Research UK, 2016). Moreover, corresponding audio content gives insights into the thoughts and emotions that people who have dementia may typically experience (e.g. uncertainty, disorientation, anxiety) as well as the typical reactions of others (e.g. concern, compassion, help) (Wijma et al., 2018; Alzheimer's Research UK, 2016).

These research findings have led the project in different directions to explore some of these concealed layers of the disease. In the following chapter, the design strategies which have been implemented in *'Persona'* are outlined. That includes multiple visual narratives that highlight the human side of the disease, and in doing so, create an immersive settings which evoke and invite the visitors' engagement and reflection as the most valuable commodity and the main target.

4. Process

This creative process has been an *iterative process of discovery.* Research studies instructed visual communication practice and vice versa. Iterations offered new knowledge, understanding and gave the project an increasingly precise vision and scope. Both the new findings and visual output have been altered and adjusted in response to the key question of the project. The project development is reflected in the progression of the research studies over the course of the master program. To present this process, I am using the emerging research questions, connecting them to the visual output as well as case studies that provided insight and inspiration.

Starting the MA program in visual communication at KMD in 2019, I built on the theoretical and practical background from my bachelor studies in photography and visual arts and my interests in the notion of memory and perception. I focused primarily on the impact of our life journeys and how our understanding of the world shapes our characters, which I already discussed in the introduction. I wondered how design and visual communication in particular could create a narrative that shows our uniqueness and portrays our human qualities. I wanted to underline what we might lose as a result of miscommunication or lack of awareness.

In order to start my experimental inquiry into the field of design and communication behavior, I posed the following fairly open-ended questions:

How can visual communication help to make us reflect about the world around us?

How can design help communicate our behaviors and perception of the world?

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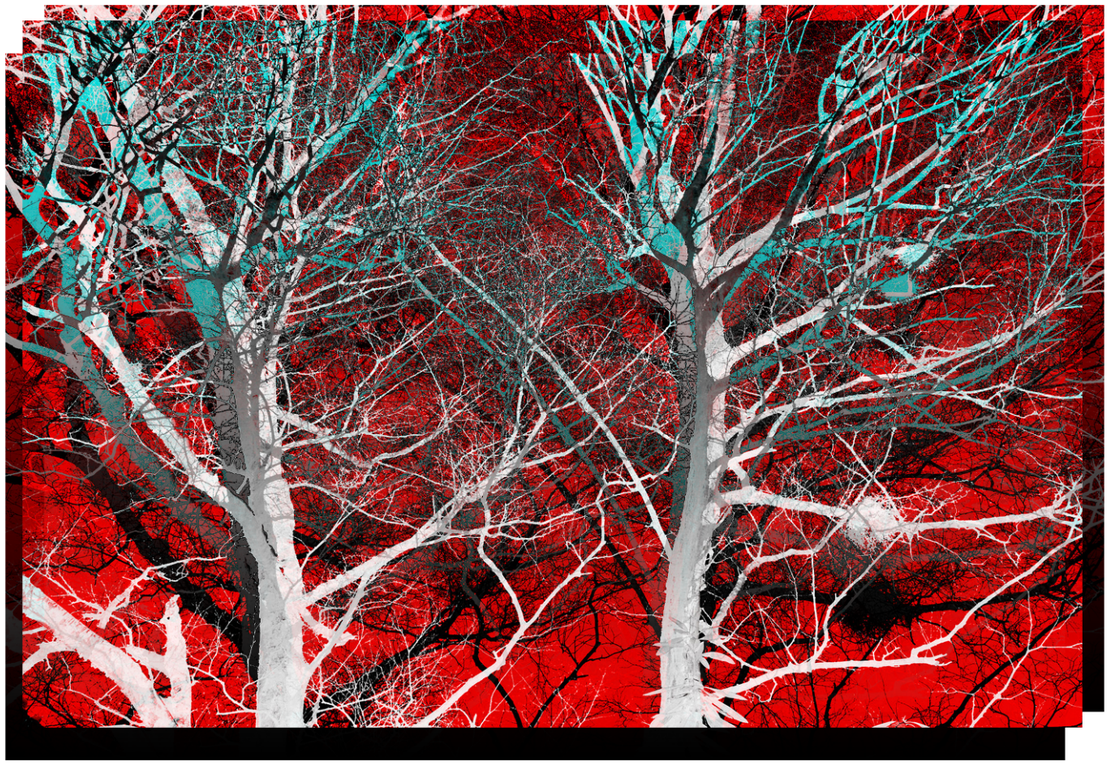

4.1. Early stages

During the first weeks of my studies, I created two visual responses to those questions. The first one was in the form of a *one-take* video in which I introduced myself and the project to my fellow classmates and teachers. The other was the first visual manifestation of my project, called the *Power Object*. The one take exercise allowed me to think about what is important to me personally when communicating with other people.

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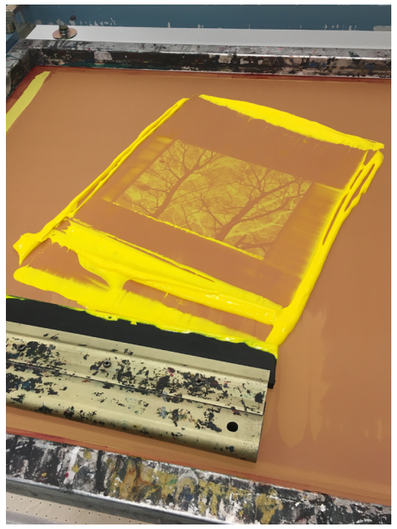

To complement that initial endeavor, a lot of ideas around the relationship between a person and space, space and an object/material, and the ergonomic or cognitive relationship between person and object/material have been tested. Through these, I examined various forms, materials, and spatial engagement. Consequently, I was able to define various form characteristics, think about their impact on the surroundings and the feeling they may create. Those associations provided tangible opportunities to combine and formulate a visual concept. Then I thought about how different perspectives could change our frame of thoughts, meanings and shape our world around us. The Power Object (Figure 5), which was tutored by Charles Michalsen was the first attempt to critically reflect on communicating such themes based on visual communication methods. As I started examining these ideas, I found the practical ways to formulate a more cohesive message. Using techniques like silk screen-printing, laser cutting and woodworking (Figure 6-8), I was able to visually manifest a sequence of frames, presenting captured moments that would otherwise be lost as a distant memory, regretfully gone unnoticed in life, transcendent moments that are underappreciated and easily escape our attention.

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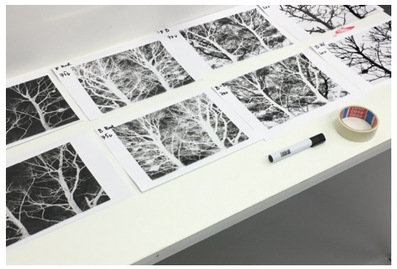

In that way, the Power Object built a foundation for further exploration along the way. Thus, the general themes of perception, memory as well as misinterpretation have been established in the early weeks of my project and are reoccurring throughout the process and in the final work. They impacted the following ideation as well.

| 8 |

4.2. Ideation

Following the first visual experiences, the subsequent research questions were investigating those overarching themes of *perception* and *memory*, leaning towards dementia and its association with memory loss and sensory impairment.

How does one's perception of the world differ from someone dealing with dementia?

How can design challenge the negative stigma of those living with memory loss and sensory impairment?

How can visual communication share a more holistic narrative about sensory impairment?

While I was investigating these questions, many quick and raw ideas came to mind. The ones I continued exploring, in some shape or form, provided opportunities to see glimpses of the world from the perspective of people dealing with memory loss and dementia. Design influences behavior, attitude and activity, or the way we hear or see things; design for dementia may essentially be design for everybody. Consequently, by humanizing the experience of those living with memory loss, we as individuals and as a society, can learn to better support and care for everyone in our community and focus on more inclusive approaches. I was inspired by Zimoun, a young artist from Switzerland. Sound is being used as an architectural feature in his installations, it creates space, and makes the spectator a part of a completely unique experience. He uses fundamental elements (cardboard boxes, cotton balls, filler wire, plastic bags, motors, and ventilators) that when combined in the right way, shape an original orchestra of sounds (Figure 9,10).

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| 9 | Zimoun (2016). *'317 prepared dc-motors, paper bags, shipping container'*. Retrieved from https://www.zimoun.net/
| 10 | Zimoun (2017). *'658 prepared dc-motors, cotton balls, cardboard boxes'*. Retrieved from https://www.zimoun.net/

All at once, these sounds define space, interacting both with it and with the audience. The result is a series of kinetic installations that form their own universe and almost seem alive.

Frequently, people who have dementia are unable to recognize the origins of sounds and distinguish between them, which can be quite overwhelming. To visualize such an idea, I started exploring ways to create a twisted environment that distorts the sounds and creates an unnerving soundscape, mimicking the hearing impairment associated with dementia. Hence, I made a small prototype that was displaying an interactive installation piece (Figure 11), in which the audience could roam around, interact with what would have been sound panels, direct the sounds around and, in return, create a chaotic soundscape demonstrating what our everyday environment might sound like to an individual with dementia.

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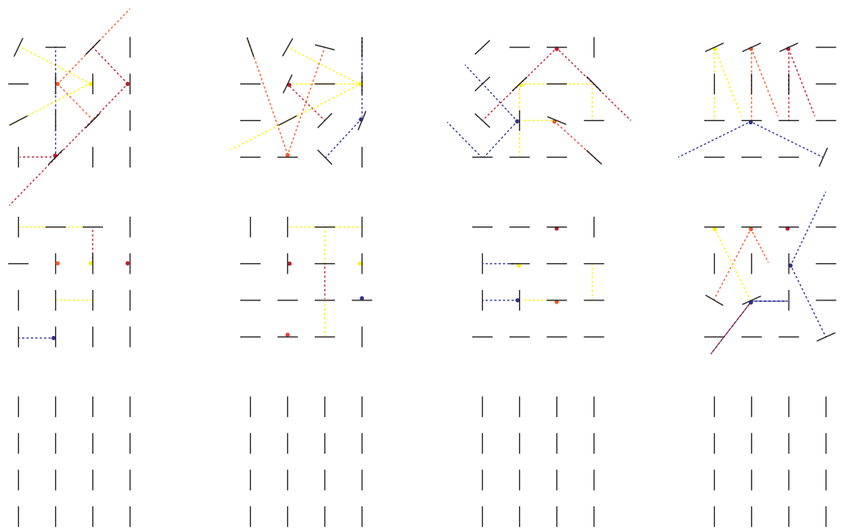

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I then further developed that concept, and considered the panels to be moveable (Figure 12), so the visitors could create new sound fields and direct sounds in multiple ways. The arrangement and alignment of these sound panels could be shifted as they would move around them. This new arrangement also created a maze-like experience (Figure 13), and in doing so, adds to the degree of confusion and disorientation, making a multilayered experience. This iteration would encourage the audience to change their roles from passive to active participants; that way they could co-create the experience, affect, and modify it.

Although this concept had allowed room for reflection, it was lacking in approach, content, and storytelling techniques. I wanted to be much more explorative, expressive and create a lasting effect. I was interested in keeping the audience in the loop and taking their attention, but I wanted to create an emotional experience that lingers long after they are gone. Nevertheless, this experiment was an interesting way to start a discussion, and further exploration of sensory impairment, particularly in creating imaginary scenarios leading the audience attention towards a positive change in attitudes. It was also an experiential attempt to use alternative storytelling. Though there has not been much follow up in working with sound impairment, the creation around sensory impairment remained at the center of my attention. Identifying the limitations of the first concept made room for a transition towards other sensory impairment. Thus, the research practice has shifted towards vision impairment. With vision, possibilities were immensely diverse; ideas were expandable in all mediums and uncovering more hidden layers of disease was feasible.

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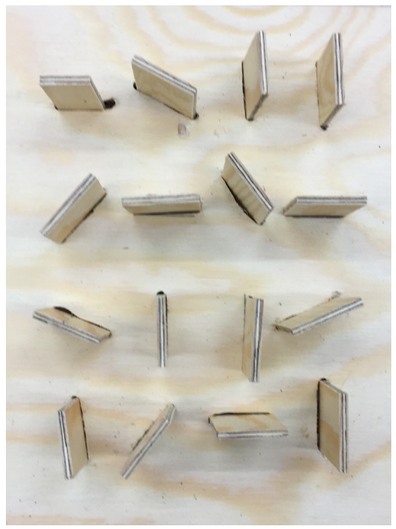

4.3. Turning point

As I was exploring different design methods and strategies, I came to realize that I do not want to focus on designing a simple solution for these impairments, but instead I want to create a sense of awareness and to empower people to initiate change themselves. I found that being able to translate research studies into a cohesive visual language is important, but creating a transitional tie to connect the findings to the target group is even more crucial.

An experiment benefiting from such a transition was tested through an interdisciplinary project, tutored by Andreas Zingerle, Philipp von Hase, Torkell Bernsen, and Petter Bergerud which we worked on besides our master projects. In a four-week project, we put into practice the entire design process, from a complex issue to a publicized design. Since our task was to use design to make the facts of the climate crisis more relatable to secondary school students, Ragnheidur Björnsdottir, Janne Maria Seljelid, Madelene Holten Larsen, Rui Liu and I were focused on topics of pollution, climate change and limits to growth. In that project, identifying a common theme (sustainable mentality) as one of the most overlooked aspects of the climate crisis initiated the research. Sustainability as a value is shared by many individuals who believe in protecting our natural environment from damage by human activities. These individuals seek to balance relations between humans and the various natural systems. However, sustainability is not just about the natural environment. It is about us humans as well, and our health. Thus, this concept was built around how we now live in a digital world, in which we need to protect ourselves and our mental health from damage by human activities. Our information-based world gives us the ability to share and collect

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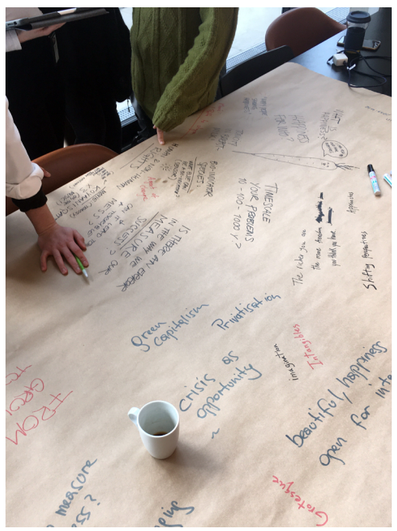

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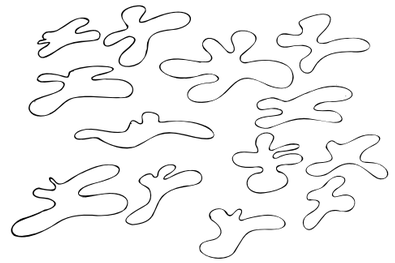

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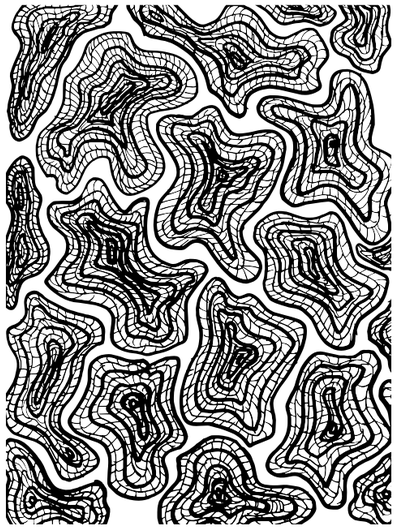

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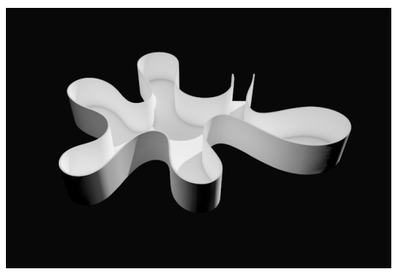

a huge amount of information, more information than we as humans can process and handle. We get overwhelmed with information every day, which has an impact on our mental health. When we reach the point when we can't process more information, we can begin to struggle with stress, self-esteem, self-worth, physical health issues, fatigue and exhaustion, memory issues and attention problems. Overload of information is polluting our minds, and it has some serious consequences we hardly ever talk about.

When we started researching this topic (Figure 14), we recognized some of the consequences and the impacts it has on us. Furthermore, we made a survey to get more local based facts and information, given that most of the information we found otherwise was very general. Once we examined the information we received, we initiated the visual concept through a collection of mood-boards. Besides, visual communication tools have been implemented to develop a language and to translate the findings into abstract forms and visual interpretations. In group discussions, we outlined various forms, patterns, and structures that were following an organic flow and smooth transition among their facets. After many iterations (Figure 15,16), a confined and compact model was built (Figure 17). This curvy and narrowed structure features mirror-like surfaces intensifying the atmosphere, bewildering the audience and overall spatial feeling. Then, we started sketching abstract ideas and experimenting with what we thought would be an effective way of communication about information overload and its effects on our minds. As a result, a collection of audiovisual content was created to represent the overwhelming effects of information overload (Figure 18-21).

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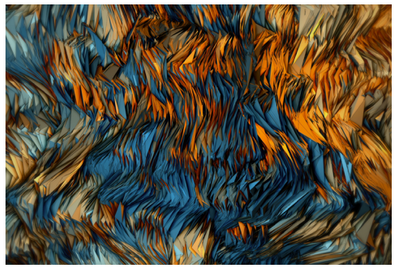

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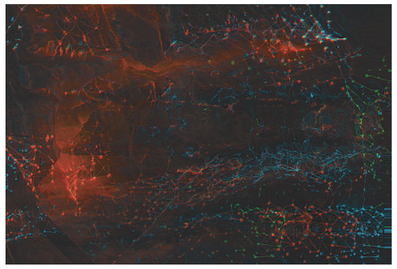

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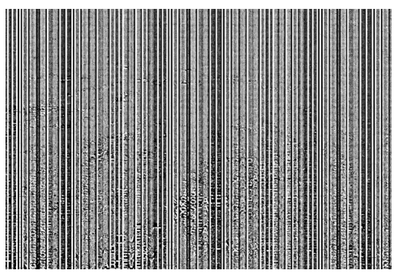

The intention of this project was to raise awareness about information overload and how it affects our emotions and mental health. To visualize the impact information overload has on us, a visual pavilion that can be experienced through virtual reality has been developed. In that pavilion, the audience dive into an experience where the information overload we experience every single day can be felt through body and mind. And in that immersive settings once an individual start interacting with the experience, the audiovisual elements appear from all over the environment, bombarding the audience with colors, motions, and other transitional phases (Figure 22-24).

This experience was a turning point and a moment of clarity for the master project. Going through this whole process laid out the blueprint of how to be transparent in delivering the message to the audience and how to build a perceptual bridge between them and what they are going to experience. It was also a learning experience, focusing on identifying basic elements for research, stakeholders, methods and developing a design narrative that was indispensable in the design process. I also learned that visual languages and semiotics affect an experience immensely. So, I could place my ideas into vessels and let the audience decode the context. Unfortunately, due to the COVID pandemic, the university was shut down and we could not make the final exhibition for the students, yet we created a remote version of the experience and shared it with the others.

You can read more about this project at *Sustainable Mentality*

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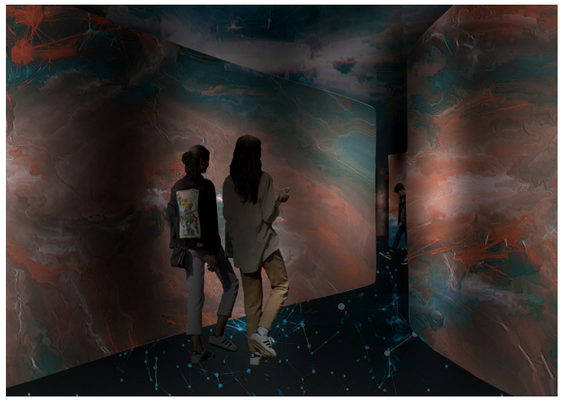

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4.4. Prototype

The complex neurological nature of dementia makes it incredibly challenging to simulate in a healthy individual. However, increased exposure to digital technologies has enabled researchers to create dementia-like experiences, allowing individuals the ability to view the world from the perspective of a person who has dementia. In addition, there are other available tools and strategies that can be used to display the difficulties of dementia and its multilayered aspects. To follow and expand this premise, I started developing a series of design strategies, rather than focusing on one platform. These ideas have provided multiple perspectives about the disease and what is beneath its surface. Although this choice seemed quite challenging and ambitious, it contributed to the key findings of the research study and what I was trying to communicate with the target group; formal and informal caregivers.

From the beginning, I was focused on finding proper ways to build a perceptual bridge between dementia's inner layers (*complexity* of the disease) and the caregivers' needs (*awareness* and *compassion*). The challenge, however, was to effectively use prior learnings and experiences to deliver a cohesive message. To do that, the prototyping phase have been divided into six subsequent sections. In each, I worked on different mediums and developed a structure describing the process. These include visual communication, memory pieces, spatial design, audiovisual content, virtual reality, and the exhibition concept. In the end, these frameworks have been merged, providing an immersive experience into someone's mind who has dementia.

Scientifically, I do not entirely comprehend what

is happening to people who have dementia and, emotionally, it is often very complicated. With these examinations, I have not attempted to explain what can happen to someone with any form of dementia. I am simply attempting to begin understanding and celebrating their lives, an endeavor that I find comforting and humane.

4.4.1. Visual communication

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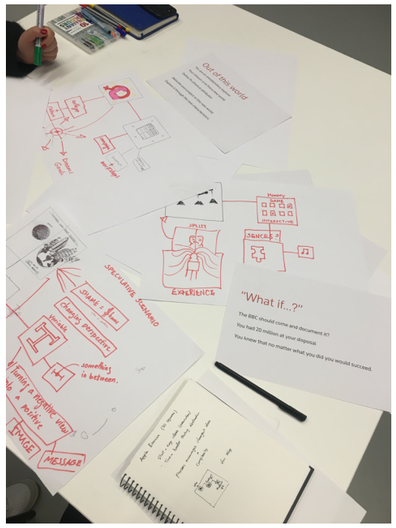

To demonstrate the inner layers of dementia, a collection of visual content has been created. Multiple tools and techniques have been tested and many iterations have been developed. These iterations included transformative ideas, fragmentation of memories, thoughts, emotions, and experiences. Ultimately, some have been used in creating separate pieces or have been combined into a uniform whole, enhancing a larger narrative (Figure 25). Before any development and to cast away any assumptions about the disease and its symptoms, a set of interviews with the specialists and caretakers was conducted complementing the literature studies and the context. These interviews were structured to engage with caretakers and those who were dealing with dementia care in a participatory form. Furthermore, they were designed to expand on the initial questions, allowing the participants to reveal and explain their feelings, experiences with the disease and about dementia care (Figure 26).

The main tenet of this approach was a sympathetic relationship between me as a designer, experts in the field, and caregivers. This sympathetic disposition created an environment, in which people dealing with dementia care can speak openly.

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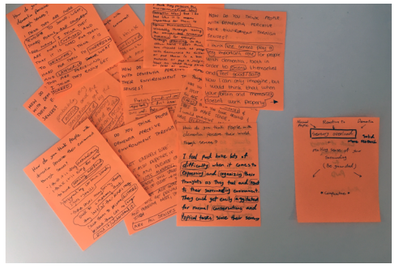

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3. How comfortable are you with dementia patients?

Hvor komfortabel er du med demenspasienter?

Vi er mest komfortable med kjente eldre demenspasienter.

4. Are you familiar with different types of dementia? If so, how does your caring shape around each specific type?

Er du kjent med forskjellige typer demens? I så fall hvordan utøver du din omsorg/praksis i forhold til personer med ulike diagnoser?

Vi er kjent med ulike typer demens som f.eks.: Alzheimer, vaskulær demens, Lewy Body, Frontaldemens(FLD), Alkoholrelatert demens, Parkinson med demens.

Ved personer med vaskulær og demens av Alzheimer type, trenger en «god nok mor» d.v.s en moderlig tilnærming. De andre trenger oftest en «god nok Far» en faderlig tilnærming som f, eks.: Grensesetting, «dette klarer du», kan ikke la pasienten ta egne valg, da de ikke vil klare dette.

Vi har andre verktøy i vår tilnærming til personer med demens som realitetsorientering, reminisens og validering. Vi kan gjøre dagen forutsigbar med skilting med f.eks.: bordkort (med navn på begge sider), skilte toalettdør og dør til beboerrom, gjerne med bilde (gjerne med ungdoms bilde, fra» den gang da» eller et kjent motiv som hytten, et kjæledyr.

This group included two healthcare professionals and two nurses who all had extensive experience with people who have dementia and worked with long-term residents. The group consists of: Cerry (healthcare professional), Kalaichelvi Sritharan (healthcare professional), May Elisabeth Høgheim (nurse), Jasmina Ramic (nurse) supervised by Eva Maria Lim (institute leader). The focus of this interview session was to refine the theoretical context and to add a more intimate, human voice to it.

The questions were divided into two categories of general and design specific inquiries (Figure 27). In the general section, it was discussed how familiar and comfortable the caregivers are with dementia and its different types, and how would they shape their care around each type specifically. Moreover, the way dementia affects the senses, the prevalence of such impairments, and the psychological and physical limitations that come with it were discussed. Afterwards, the effective ways of communication were examined, the proper settings were introduced, and the aiding plans were outlined. Finally, the caregiving challenges were explained through several examples. In the design section, the aim was to get an overview of the caregivers' knowledge about design interventions like virtual reality, and to validate the intended design choices.

By incorporating review and analysis of these interviews, the attention had been focused on the accuracy of the findings. Therefore, extensive documentation has been created, cementing user concerns in the form of notes. Consequently, a map of common themes had emerged, the differences had been highlighted, and associations had been stablished. (Figure 28) outlines symptoms that

typically affect people who have dementia as the disease progresses from the early to late stages. It demonstrates the likely effect of these impairments on the person who has dementia and the evolving role of the caregiver. It should be noted that these are general descriptions of the course of dementia, and the symptoms can change considerably from person to person and within and between the different diseases that result in dementia. Therefore, the role of the caregiver will change accordingly. In terms of design choices, creating a VR for people who have dementia was not recommended, but instead it was expressed that caregivers may benefit from design interventions like that to get more familiar with the shifting nature of dementia and its different symptoms.

| 28 |

Stages of dementia	Common changes experienced by people with dementia	What do caregivers do?
Early stage	• Become forgetful, especially regarding things that just happened • May have some difficulty with communication, such as difficulty in finding words • Become lost in familiar places • Lose track of the time, including time of day, month, year, season • Have difficulty making decisions and handling personal finances • Have difficulty carrying out complex household tasks • Mood and behaviour: - may become less active and motivated and lose interest in activities and hobbies - may show mood changes, including depression or anxiety - may react unusually angrily or aggressively on occasion.	Family members become aware of changes and may prompt the person to seek assessment (in pre-diagnostic phase) Caregivers become aware of their caregiving role (often as a result of diagnosis) • Provide emotional support following diagnosis and when the person is depressed or anxious • Prompt and remind the person about events, tasks and other things to help them maintain involvement and independence • Provide assistance with instrumental activities (e.g. personal finances, shopping).
Middle stage	• Become very forgetful, especially of recent events and people's names • Have difficulty comprehending time, date, place and events; may become lost at home as well as in the community • Have increasing difficulty with communication (speech and comprehension) • Need help with personal care (i.e. toileting, washing, dressing) • Unable to successfully prepare food, cook, clean or shop • Unable to live alone safely without considerable support • Behaviour changes may include wandering, repeated questioning, calling out, clinging, disturbed sleeping, hallucinations (seeing or hearing things which are not there) • May display inappropriate behaviour in the home or in the community (e.g. disinhibition, aggression).	Caregivers become aware of their supervisory role • Use communication strategies to aid understanding • Provide help with carrying out personal care • Provide help with other activities of daily living such as food preparation, dressing appropriately • Respond to and manage behavioural disturbance and inappropriate behaviour.
Late stage	• Usually unaware of time and place • Have difficulty understanding what is happening around them • Unable to recognize relatives, friends and familiar objects • Unable to eat without assistance, may have difficulty in swallowing • Increasing need for assisted self-care (bathing and toileting) • May have bladder and bowel incontinence • Change in mobility, may be unable to walk or be confined to a wheelchair or bed • Behaviour changes, may escalate and include aggression towards carer, nonverbal agitation (kicking, hitting, screaming or moaning) • Unable to find his or her way around in the home.	Significant demands on caregivers as the care recipient becomes fully dependent and loses the ability to communicate needs and wishes • Provide care, support and supervision around the clock • Provide full assistance with eating and drinking • Provide full physical care (bathing, toileting, dressing, mobilizing) • Manage behavioural problems.

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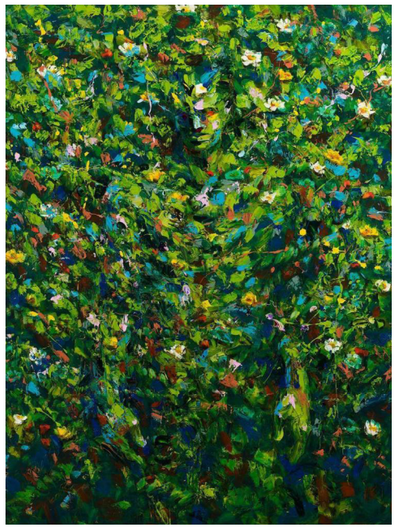

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Following what I learned from this approach, I wanted to encapsulate the essence of these associations in my master project. Therefore, I decided to create an immersive experience that raises awareness about dementia and its multifaceted nature. The first concrete concept I was working with was to see the people and not the disease; It was about inclusiveness and humanizing dementia. The line of thought was: As a society, we have dehumanized people with dementia for far too long. We have forgotten that there is a human being who is undoubtedly feeling very vulnerable. We have made people dealing with dementia and their caregivers feel very alone and very isolated– in fact, there has been a great disconnect.

I was looking for inspiration in art and design projects which portray an energy, a kind of pent-up force of movement. Such projects that inspired me, both conceptually and visually, were Salman Khoshroo's oil painting *'Blend'* (Figure 29) and his *'Wool on Foam Portrait Series'* (Figure 30). He plays with the expectations and perceptions of the human image and fills his figures with joyous emotional vibration. He describes: *"it is an obsession to take inanimate materials such as paint and shape it into a face that embodies a human soul. By soul, I don't mean a religious or spiritual notion, the idea is more about emotions, intelligence and character."*

| 29 | Salman Khoshroo (2018). *'Blend'* 120x150cm, oil on canvas Retrieved from http://salmankhoshroo.com/?p=1112
| 30 | Salman Khoshroo (2020). *'Wool on Foam Portrait Series'* 20x20cm Retrieved from http://salmankhoshroo.com/?p=1448

I also found Espen Kluge's *'Alternatives'* portraits to be explorative with a rainbow of colors and emotions (Figure 31). Although the details of the expressions are abstracted into masses of colorful geometric threads, his portraits display a spectrum of the human mind. This is especially fascinating when you consider that Kluge is working in the genre of generative art, often criticized for being cold, geometric, and esoteric. He gives generative art a dynamic and new direction with work that is universally approachable, warm, and equally accessible to both the heart and the mind.

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| 31 | Espen Kluge (2019). *'Alternatives'* Retrieved from https://www.espen.xyz/alternatives-alternatives

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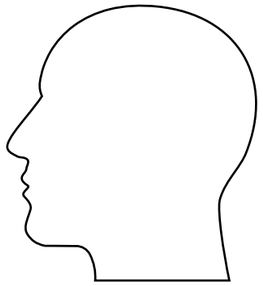

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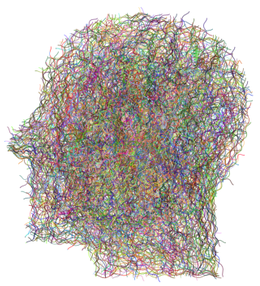

Similarly, I attempted to expose the inner architecture concealed beneath the surface of the human form. I wanted to emphasize that every mind is like the ocean; there is surface and depth in all of us. The late Agnes Varda beautifully described that frame of thought: *"If we opened people up, we would find landscapes."* We all can relate to sadness, joy, fear, grief, and anxiety, and happiness. People who have dementia share the same sentiment. Unfortunately, emotions confuse them and us. Thus, I tried to encapsulate that idea by illustrating the similarities that are shared among all of us.

As I was exploring ways to illustrate these similarities, I figured I want to focus on our imaginative devices. So, I drew an objective form of portraiture (a human face silhouette) (Figure 32), and I tried to fill it with symbols and landscapes representing memories, thoughts, emotions, and motives of someone who has dementia (Figure 33). First, I made various symbols on a small-scale, then I covered the whole silhouette with those layers in different orientations and sizes. In some cases, the arrangement and details of the pieces have been changed multiple times. Some have been colored while others remained in black and white. The addition of color changed the overall look and aesthetic (Figure 34,35), but I thought Instead, I would prefer to let the audience reconstruct the images and make their own stories. I wanted them to color the silhouettes with their own imagination. Following this, a sequence including twenty-four frames had been created (Figure 36).

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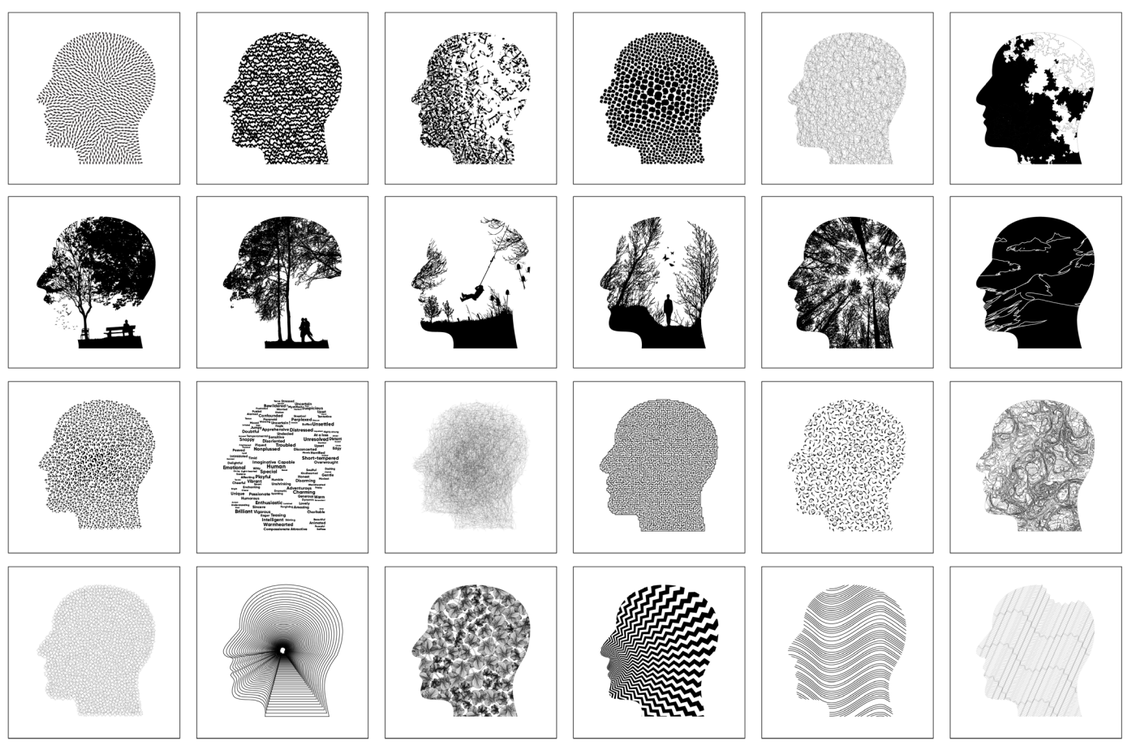

Next, these silhouettes were engraved on acrylic plexiglass (1 mm) on a very small scale (13 x 13cm). Subsequently, I made a holder box to mount the layers and create an overlapping effect (Figure 37,38). While some shaped interesting combinations, a few others have been misleading because of their density. In those cases, the illustrations have been altered. Once again, many iterations have been developed before reaching the final outcomes, allowing the process to grow organically.

Once there were six variations for each theme, the illustrations have been engraved on larger acrylic frames (40 x 40cm). As a result, the illustrations have been spaced out nicely, creating clearer and visible details. In this case, thicker layers (3 mm) were used to add more stability and depth to each frame. I also placed the layers on a wooden holder instead of a synthetic material and used a movable spotlight to shine light on the illustrations. And finally, I built a wooden shelf (64 x 42cm) to evenly stack the extra

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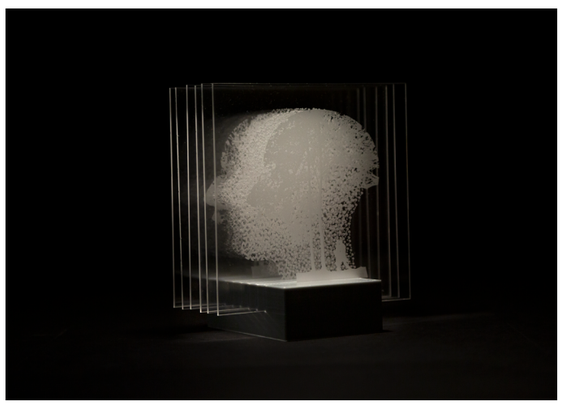

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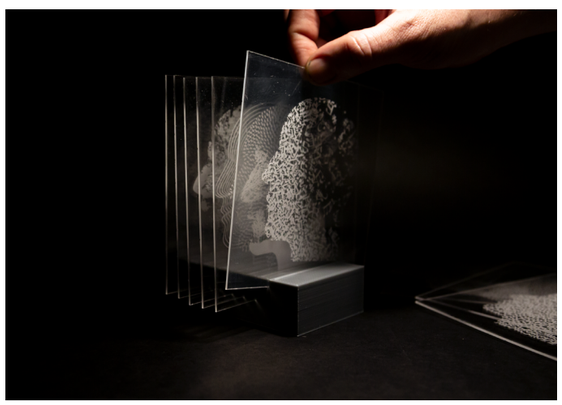

layers without leaving scratches (Figure 39). While the interchangeable frames and wood textures added an intimate layer to the piece, allowing the audience to interact and co-create the sequence, the movable light added another dimension to the piece: time, leading to a smooth transition between the layers and thus, creating a mobile piece. This combination (Figure 40-42), invites a subjective point of view but can only be viewed from certain angles; from above and the side it vanishes, and the viewers suddenly find themselves staring into a void.

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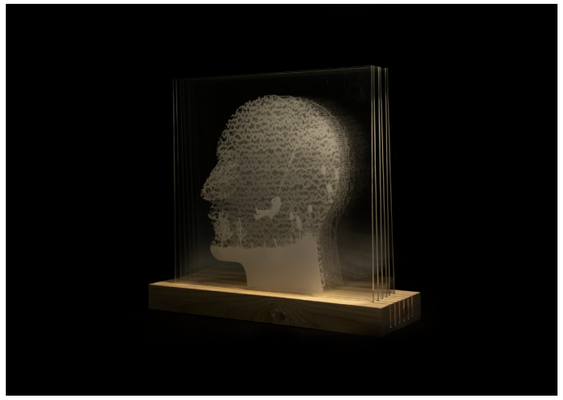

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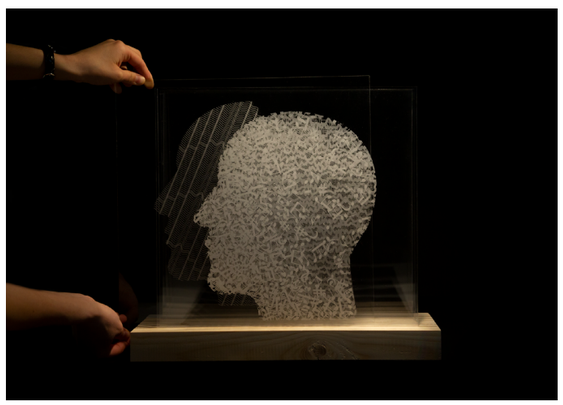

| 42 |

4.4.2. Memory pieces

The pleasure of remembering is common among all of us, yet it is frequently overlooked by the lack of understanding or limited perspective. People who have dementia wander around in time. They are nomads in their own history and future; a place where there is no beginning or end. But we are not so different; we all get lost occasionally, sometimes by choice, sometimes due to forces beyond our control. It is only when we learn that the path presents itself. Hence, it does not take a professional to harness the power of creativity to relate to those who are dealing with memory loss and dementia. It only takes a person intuitive enough to realize while dementia brings declines in some areas such as short-term memory, it can also bring out unnoticed strengths and joys that can offer just as much pleasure and enjoyment in life.

That narrative shaped the initial idea for the second piece; to further explore an overlooked aspect of dementia and to uncover another intimate layer beneath its surface- remembering; something very familiar to all of us. The layers of memory that we all have, some closer to the surface and clearer than others, those that can have quite an effect on our identity, and that of people who we share these memories with. In this attempt, I wanted to illustrate that while details get gradually murkier and more unclear as someone's memory regresses due to the progression of the disease, the core and the identity remain intact. The cheerfulness, liveliness, and many other characteristic ways of handling things which are deep inside stay forever.

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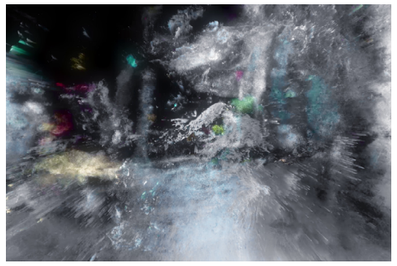

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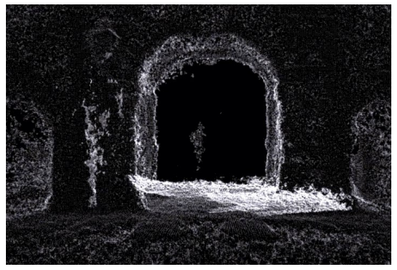

Visually, I was very much inspired by many of Fuse* projects such as *Snow Fall (2019), Van Gogh in Me (2020), Treu (2020),* and *Mimesis (2020)* as their works no longer attempt to reflect reality but begin to imagine new scenarios (Figure 43-45). Their objective is to push beyond accepted boundaries, spur empathy and seek out new connections between light, space, sound, and movement. While their installations begin with widespread data integration, the processes and outcomes reveal the essential bonds of communal experience that bind us. They invite us into alternate realities, worlds that exist only as a projection of our own collective daydreams.

| 45 |

| 43 | Fuse* (2020). *Treu* Retrieved from https://www.fuseworks.it/works/treu/
| 44 | Fuse* (2020). *Van Gogh in Me* Retrieved from https://www.fusefactory.it/projects/
| 45 | Fuse* (2020). *Mimesis* Retrieved from https://www.fuseworks.it/works/mimesis/

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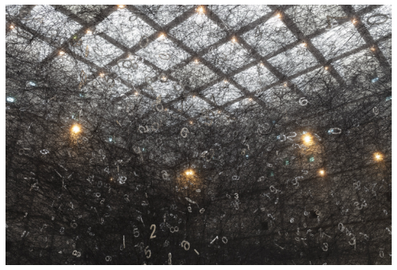

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'Counting Memories' by Chiharu Shiota was another intriguing piece that hugely inspired me. In her installation, the large cloud of entangled string reflects our history, while the numbers scattered sporadically like the stars represent the most meaningful dates we know. They define us individually but also connect us universally. At the center of this universe, something yet to be seen; our past, present, and future selves (Figure 46,47).

To evoke familiarity, I decided to use a visual language many of us are familiar with: representing a glimpse of someone's memories. This metaphoric depiction has been created to display the passage of time and many memorable events or experiences that come with it. It has been focused on celebrating a feeling of nostalgia, to underline the episodes and adventures that might become cloudy yet are cherished forever. Subsequently, I developed a character and a narrative revolving around this: Gro, who has recently been diagnosed with dementia, starts to remember her past; her childhood, youth, and adulthood. She remembers moments that were full of joy, curiosity, and a sense of discovery. Experiences that made her character. As she reminisces about her past, she remembers her parents, their affection for her, and their everlasting love. She recalls her friendships, how she enjoyed her time, some of the discoveries she made. She sees her partner, the delightful moments they shared together, and she remembers her granddaughter. She lost her sense of time, looping into unceasing events.

| 46,47 | Chiharu Shiota (2019). *'Counting Memories'* Retrieved from https://www.chiharu-shiota.com/counting-memories

Through digital illustration and by using image manipulation techniques, I was able to develop a sequence of images representing moments floating from the past to the present. Next, I needed to find a way to blend the layers and create a transitional effect. Initially, using applications like After Effects seemed like an option, yet the overall effects were quite different from what I had in mind. Other 3D/ animation applications like Cinema4D and Blender needed heavy processing and were not optimal for this development as well. That is why I used a creative coding application called Processing. *Processing is a flexible software and a language for learning how to code within the context of the visual arts.*

While this application was totally new to me, and it took me a couple of months to start making anything sensible, the process has been immensely enjoyable and productive. The first attempts were nothing close to my expectations, but after many iterations, I wrote a series of algorithms to display a sequence of images floating in a three-dimensional space. In the following, an overview of this process and some of the main changes have been described.

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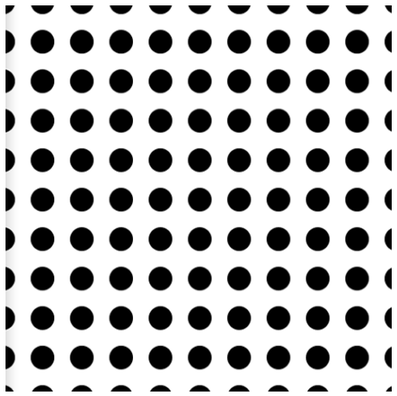

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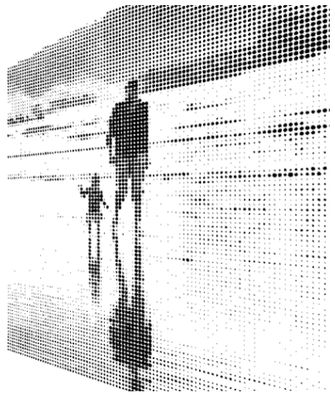

First, an image has been loaded and resized into an empty canvas, then the background has been removed to create a simple multiply effect (Figure 48). But the intention was not to redraw a flat image, instead I wanted to translate an image into particles floating in three-dimensional space. To do that, I needed to analyze the image, get its pixel data, and then draw ellipses on a grid that represent the brightness values of the image. So, a loop of ellipses has been scattered around the canvas, but this randomness needed to be controlled. Therefore, a grid has been created to scan the image and check the color value of each pixel (Figure 49).
Technically, a color is always a RGB value, but I wanted to have a single greyscale value that I could convert into the size of the ellipses. So, I mapped the brightness into a new range and translated the pixels across the sketch window. As a result, the image has been rasterized.

Next, I figured a way to rotate the image around its own center, but once again the outcome was quite flat (Figure 50). To make the visuals pop up, the tiles have been distributed on the Z axis. This had resulted in a 3D effect, but the downside was the lack of depth in ellipses. Instead, I used spheres to create a more natural visualization. Following that, the spheres have been moved in and out of the canvas to create the floating effect (Figure 51). The floating effect added another dimension to the piece, time. That way, the image was no more static, and instead had an ephemeral effect. In the feedback sessions with Cathrine Kramer (associate professor) and later with Torkell Bernsen, it was stated that maybe a change in color tone could lead to a different feeling. So, the next iterations have been focused on the inversion of the colors, and the addition of

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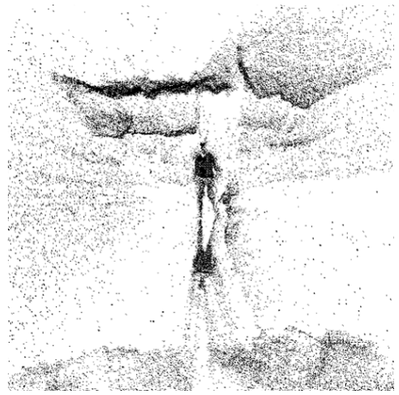

various color tones. The monochromatic tones had given different textures to the canvas; the greyscale tones separated the particles sharpely, the RGB tones created a vintage cyanotype aesthetics, sepia tones added a layer of rust indicating nostalgic feelings, and the full spectrum tones shaped a vivid and lively output (Figure 52-55).

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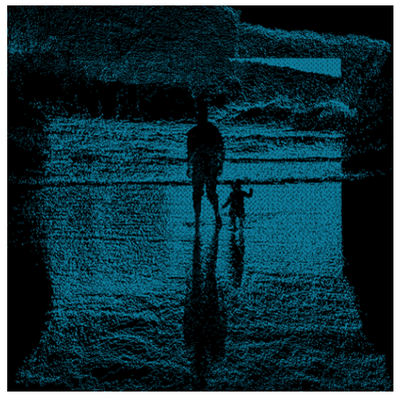

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The final output was built from the summation of the original rasterization and the inverted piece in sepia tone. In that case, a sequence of floating images was created giving a fragmented glimpse of Gro's memories (Figure 56). Then, the final sequence has been tested and projected on various surfaces like concrete, fabric, and wood. Each of those variations gave a distinct texture to the piece based on the light settings available. Some dissolved a portion of the particles and the others created much more solid outcomes. Besides, the quality and sharpness of the particles have been altered differently in each texture (Figure 57-60).

Since the main intention of this piece was to find the proper way to bring this narrative from the screen

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into life, none of these surfaces fitted the context and its emotional textures, instead they detached from it, making it look flat. Through these explorations and by examining the effects of these textures on the visuals, I found out what is lacking in this context. When we recall past experiences, we search through what has been encoded in our bodies. Thus, our brain recreates and reinterprets a hazy version of those memories through embodiment and expressions. That is why an external, flat surface does not provide the emotional context of such memories.

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Like a canvas, the human body manifests the experiences that shape and mold us. While we can sometimes choose the colors that often are thrown at us, we are left to reconcile the new paint on the canvas. Do we gloss over it or weave it into a new image? Here, Vilde's body is covered with her grandma's (Gro) past experiences and memories, dressed with sensuality. Part of her character is influenced by her grandma's, but the remaining is left to her, ready to be written with her own story.

The double exposure imagery here is another way to understand how our lives are influenced by the passage of time and how the experiences that move past us are drawn into us and shape who and what we are. The combination of projected mapping visuals blends and transforms with real shadow created by the projector and a softbox light (Figure 61-63). This visual narrative elicits a nostalgic feeling that demands and challenges the audience to give up their own persona in order to immerse into someone else's.

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4.4.3. Spatial design

The previous experiences with the sound panels concept and the group project had benefited from a spatial element: a maze-like environment. Through extensive research, maze-making exploration and by examining varied themes and functionalities of the mazes and labyrniths, a puzzling space has been created, providing a spatial perception of dementia and its confusing nature. In this attempt, not only the entropy and the shape of the model have been altered, but the reason behind designing a maze rather than a guided path like a labyrinth has been thoroughly examined. Besides, other elements have been added to create a more sophisticated and elusive surrounding. The outcome has been extensively used in a VR application and has been printed for the final presentation.

From the unexpected twists and turns of the labyrinth in the *Greek myth of Theseus and the Minotaur*, to the intimidating network of hedges in Stanley Kubrick's *"The Shining"*, mazes have a distinct and mysterious allure. They have a human quality as well, as they are shaped by the desire to weave stories from abstraction into paths and barriers that give them meaning. They may be spiritually soothing or visually appealing, and they may give rise to feelings of panic, excitement, or serenity (Figure 64,65). But mazes have a life beyond the plot lines of ancient myths. They exist in scientific laboratories and even, it can be said, in the context of our journey home from work, and in our minds.

However, not all circuitous paths are labyrinths. For example, mazes are completely different; they may have one correct route but are designed to trick someone into getting lost or hitting a dead end. If you associate the term "labyrinth" with

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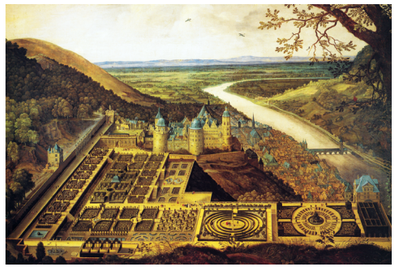

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| 64 | Jacques Fouquières (circa 1620). *The Gardens of Heidelberg Castle*
| 65 | Lodewijk Toeput (circa 1579-1584). *Pleasure Garden with a Maze*

the *Minotaur of Daedalus* or David Bowie's *Goblin King*, you have been misguided. Unlike those pop culture mazes; real labyrinths only have one path and contain no wrong turns. In other words, they are not puzzles; they are meditations. In fact, a maze is a "multicursal" puzzle, it has a multitude of ways to go and decisions to make. Getting lost in a maze is trivial, but there are often short cuts. On the other hand, a labyrinth is "unicursal", it offers one route that you may feel is taking you in all different directions but will ultimately lead you to the center (Lupton, 2017). A labyrinth may take you a long time, but you cannot get lost if you follow the path (Figure 66).

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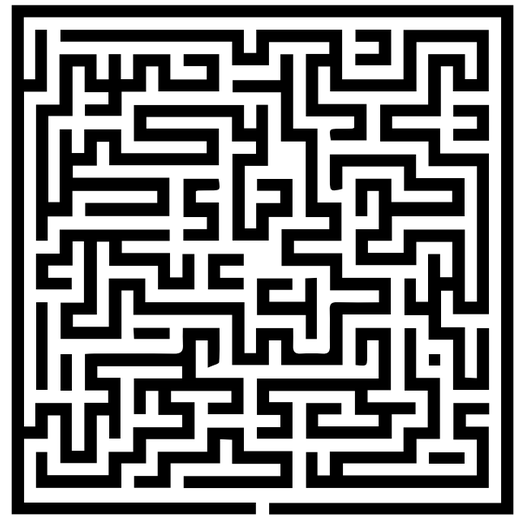
Labyrinth Long, guided path



Maze Puzzle designed to confuse

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Mazes have always been elusive, puzzling forms of architecture. Although less seen in its physical form nowadays, this experiential archetype has been given a fresh, dramatic, and performative spin by many artists and designers. *"The maze is, on the surface, a dazzling and photogenic array of spaces but, upon closer inspection and attention, is also a lens through which to consider contemporary modes of operation"* says Rafael de Cárdenas (Keh, 2018). A maze offers ever-elusive opportunities of getting lost. This is essentially visible in a painting called *'Labyrinth'* by Kenne Grégoire (Figure 67) or in Kevin Allen's massive installation piece, The BIG Maze at Washington DC National Building Museum (Figure 68). Once I started to apply this relationship, visual associations emerged across materials. I figured there was a short leap between storytelling structures and the role of patterns in architecture with intertwined concepts like texture, textile and tessera. Excited to dig into these ideas, I began sketching the maze model.

Structure

To formulate a form that matches the context of the project, I started with some open questions about the structure of the experience. How might the qualities of a form translate into navigable elements of a maze? To examine that, I sketched different variations, which in those, the walls, paths, entrances, exits, spirals, and loops were added in the subsequent phases; in some forms there was an order, and in others entropy was reigning (Figure 69). The first attempts have been quite rigid. So, I simply started with a square outline and added more blocks within the main frame. The entropy and complexity in those variations have been shifted throughout. Moreover, multiple position options have been considered for the start and end points of the maze (Figure 70).

| 67 | Kenne Grégoire (2016). *'Labyrinth'* Retrieved from http://www.kennegregoire.com/pages/not-available.htm
| 68 | Kevin Allen (2019). *The BIG Maze* Retrieved from https://www.nbm.org/exhibition/the-big-maze/

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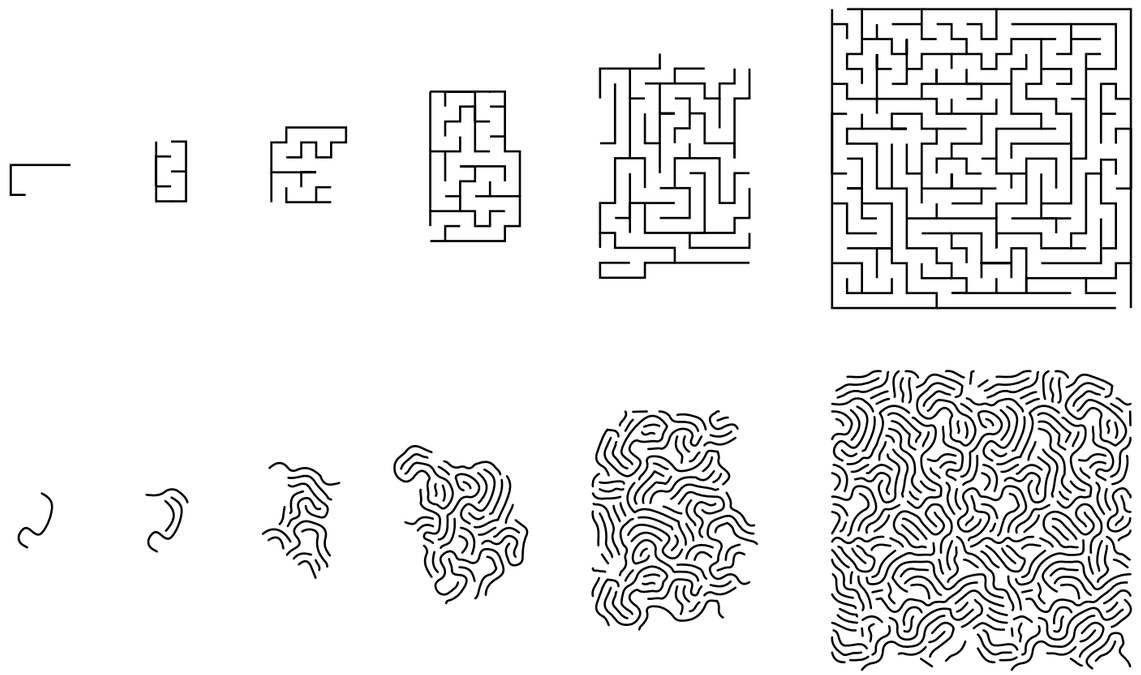

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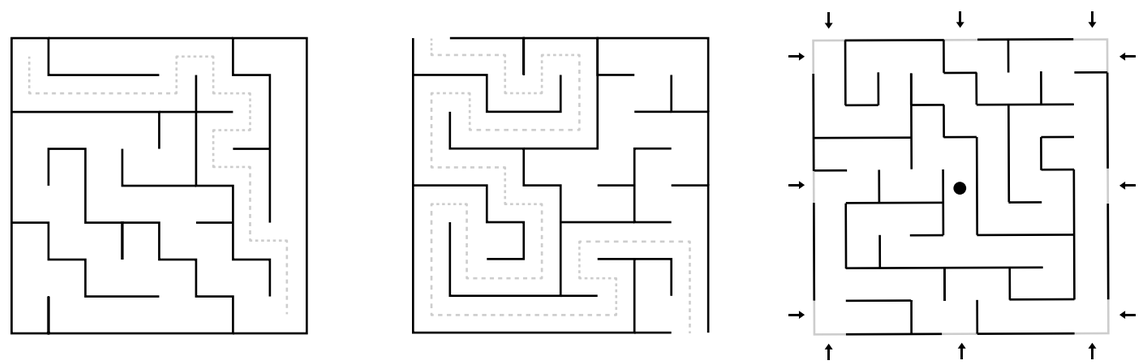

These early iterations made me realize that enough irregularity could change the overall effect and lead to a more organic form. So, instead of adding more routes, I thought about other possibilities that could shape fluid forms. Looking back into earlier research studies about the brain and how neurons transmit information throughout the body helped me consider human brain shape and the way gyri and sulci form the folded appearance of the cortex (Figure 71). Thus, the stem of the maze has been made to resemble a human brain rather than a geometric form. This major change has widened the form into a series of roots spreading across the base.

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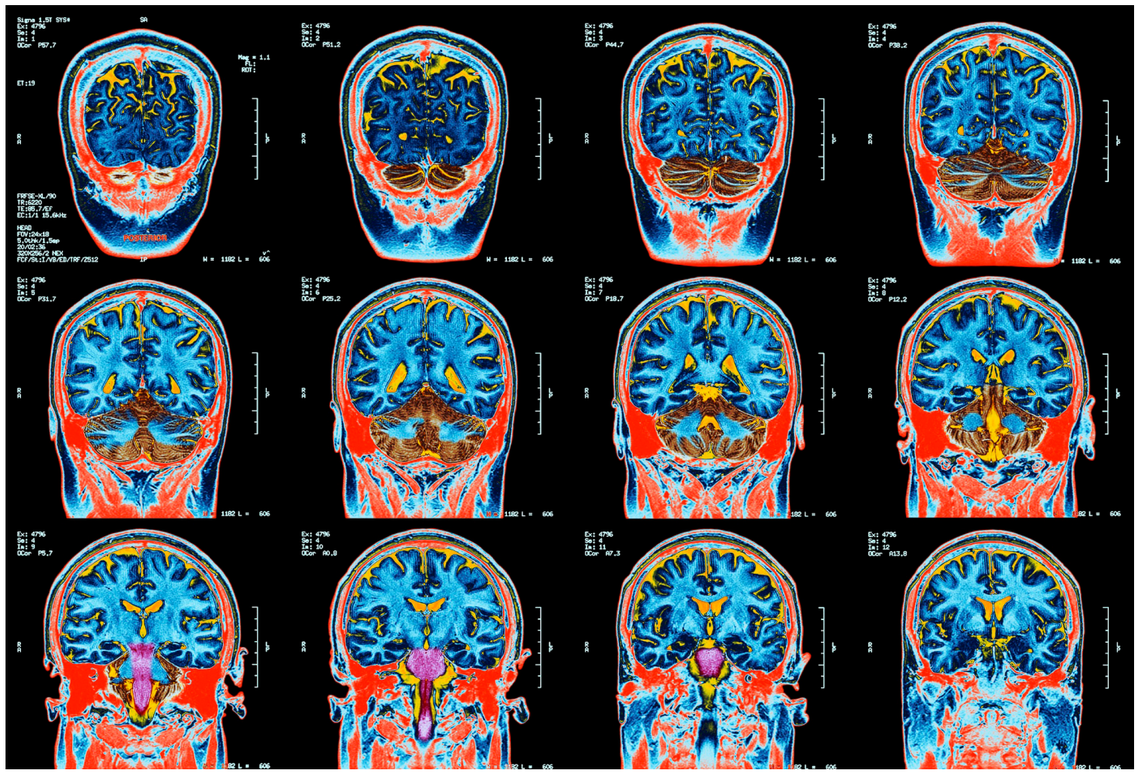

| 71 | Photo courtesy of Science Photo Library, Getty Images (2019). *Brain MRI Scans*

In this form, some walls were thinner. That meant they had fewer intersections, adjacent lines, and were less detailed or specific. And thus, they could easily blend into the texture of the maze. This quality has made them more versatile. Even though it was possible to build a whole maze from the thinner walls, the lack of diversity could lead to a chaotic and quite dense distribution of the walls. Therefore, wider surfaces have been added frequently on the opposite side of the thinner walls, stretching the model around. In addition, their complexity has given the form a voice (Figure 72).

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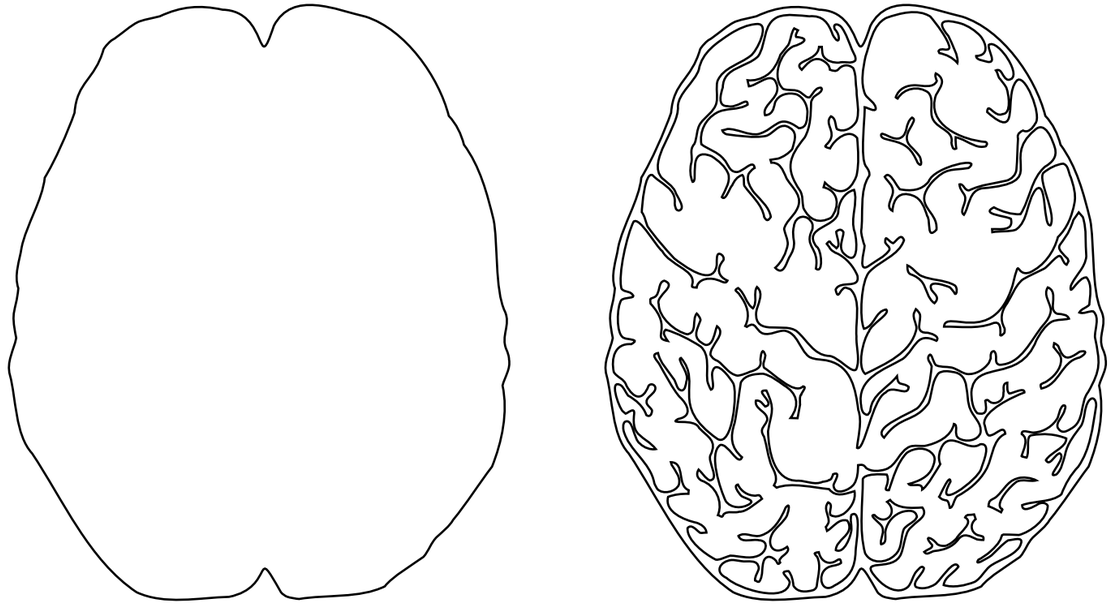

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Continuity

There are all sorts of visual and conceptual relationships embedded in the design of a form, particularly, one inspired by the human brain. So, a sequence of topographic maps has been drawn to display the impact and frequency of intended visual content. Furthermore, these depictions provided hints of the approximate triggered zones and eventual events, something essential for mapping the audio and visual content in the environment in the later stages of the process. While some shared the same flow, others came in pairs or evolved from the same anatomy. These flips and switches between neighboring walls have given an organic continuity to the design. Furthermore, these combinations allowed me to subtly shape the texture of the maze while pushing the path in new, unexpected directions. With this manifestation (Figure 73), I was able to keep the eye moving, challenge the audience and invite them for further exploration.

Visual Rhythm

The model was designed to deliberately disorient and surprise the audience, so it was essential to find a balance between the uniqueness and utility of the sections. To do that, I used assets like doors and stairs to break up the maze sections and to divide the flow of movement in the space. These rooms and segments were mounted on the walls or were attached to the ceilings connecting the floors to each other (Figure 74). In addition, each lobe of the maze included a few rooms and at least a set of stairs, contributing to a smoother transition and effortless exploration (Figure 75).

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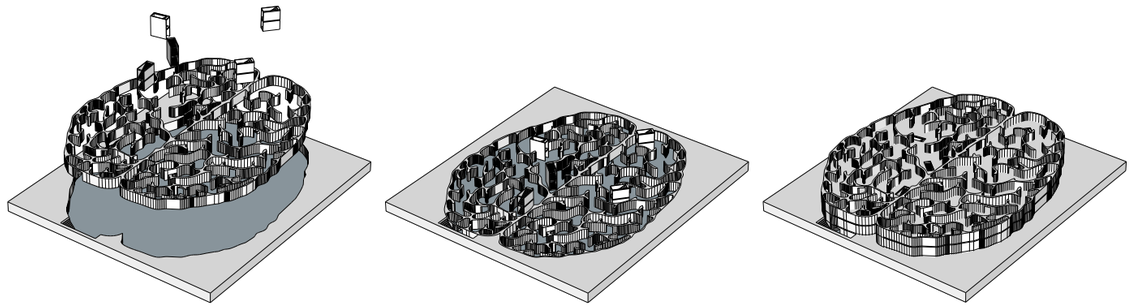

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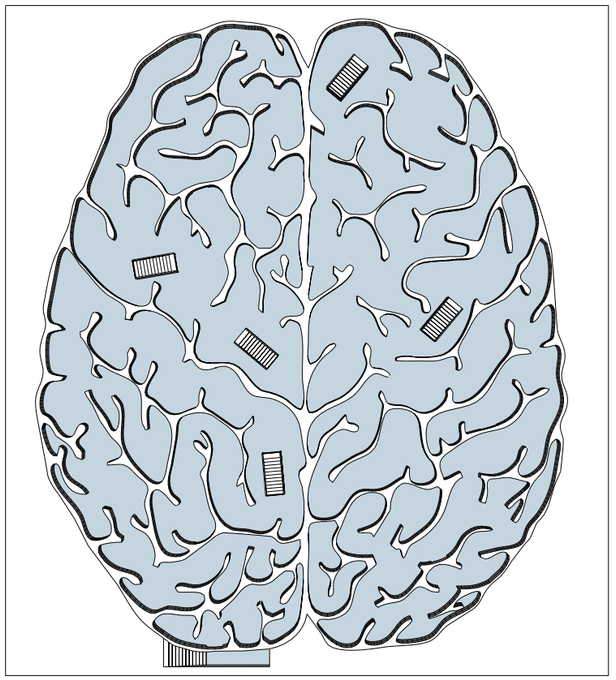

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Flexibility
I explored the 3D model of the maze from various perspectives once the assets were assembled. Using Sketchup and Unreal Engine, I was able to virtually walk around the environment (Figure 76), check if there were any sort of issues with the measurements, distances, walls, and stairs. The ability to walk instantaneously from one room to another or take the stairs and see the other floors has given an estimated visual representation of the model. Therefore, some spaces have been tightened up or some others have been widened to intensify the feeling of disorientation. Furthermore, the height and width of the walls have been altered, providing enough free space for the audience to fit into the environment.

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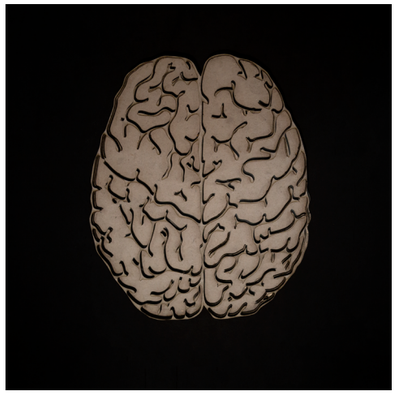

Output
Once the 3D version of the model was done, I tried to make a few small prototypes to get an estimation of its proportion. Since the model had many vertices and curvy paths, using a 3D printer was not an ideal choice because the filament could have spread inconsistently, causing epic failures. Instead, I used the laser cutting machines to cut the maze paths and outlines. First, several thin layers (2 mm) of the maze's walls were cut on cardboard sheets (Figure 77,78). Then, those pieces have been glued together to represent a floor. Finally, an outline of the maze was cut as the base of the model. Interestingly, the laser beam left a bit of burning marks around the surfaces of these layers, which in a way has given an abstract feeling to the printed model.

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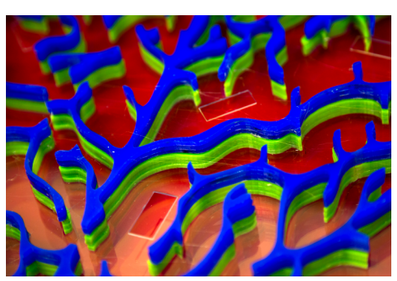

Continuing with the same strategy, I used acrylic plexiglass for the second print. In this case, the model has been cut on a larger scale using different colored sheets. To extend the height of the floors, three layers (3 x 3mm) have been put on top of each other, giving more depth to the model. In addition, a couple of transparent layers have been cut for the ceilings, stacked between the floors. Although the transparent layers provided a new perspective into the hidden layers of the model, the overall aesthetic seemed clinical (Figure 79). I wanted something more inviting, a material that could add a texture to the model instead of detaching an element from it. Therefore, I tried to find the most suitable material for the final print.

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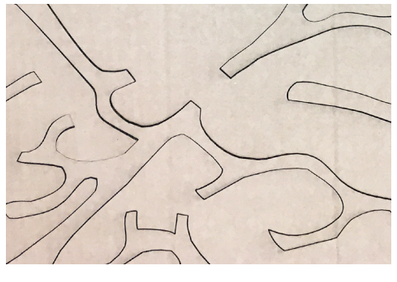

In discussion with Svein-Petter Knudsen (associate professor) and Fredrik Salhus (chief engineer, foreman model workshop), we explored the optimal way of cutting the model. By comparing different materials, their appeal and what they are contributing to, we landed on multiple options. One option was to 3D-print the model using wood filament. However, when I tried this in small samples, the outcome was once again creating a disengaging texture. The other option was to use clay, though a large-scale clay printer was required, and was not available. The optimal choice was to cut the model on wood, considering its emotional and inviting texture. Especially since the wood texture engages all the senses. Its surface has a warm, affecting, tactile, and sensorial strength, while the depth of individual grain and the range of hues delights the eye. To examine these effects, small samples of the maze model have been cut on plywood. Then its size has been readjusted for a large-scale print (Figure 80). In that case, three

layers of the model (105 x 90cm) have been cut on MDF (12 mm) with a CNC machine (Figure 81,82). Moreover, to separate the boundaries of the model from the outside area, I made a frame filled with porcelain sand around the maze. Compared to the rigid, constructed walls of the maze and its surface, the sand fluidity and softness created a contrasting effect inviting a meditative reflection on the model and what it represents (Figure 83,84).

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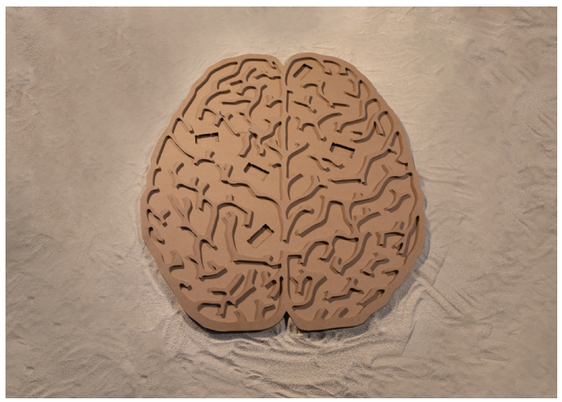

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4.4.4. Audiovisual content

To create an immersive virtual reality and to enhance the maze atmosphere, a series of audiovisual content has been created. While the maze model has been designed as a visual metaphor for the way people who have dementia experience an environment, the audiovisual content explores the symptoms and their effects.

As dementia progresses, familiar places can grow increasingly foreign and confusing. The effects can be like living in a continuous present; you can never really remember what room you came from or plan what room you are going to visit next, thus you feel surrounded or trapped. But disorientation is not merely caused by spatial difficulties, it is also intensified by visual misinterpretation. I wanted to create a sense of unease that might mimic a dementia experience, to evoke emotions by making the audience a participant in the piece and by going so far as to place them in the space of someone's mind. My hope was that they might feel deceived or misguided, imitating the mistrust that I imagine someone dealing with dementia feels. To implement these, the visuals are designed not only to illustrate the common symptoms of different dementia types, but to highlight their overlapping effects. For instance, memory formation difficulties, having trouble understanding visual images and spatial relationships are the focal points of the Alzheimer's disease content. Mood swings, concentration problems, and disorientation are at the center of Vascular dementia content creation. And hallucination, slowness, and navigation problems are the essential components of Lewy body dementia content. While each group elicits a distinct feeling, getting emotional, confused, and disoriented have been shared throughout.

From Intellect to Perception
I was exploring the idea that someone who has dementia has been forced from a life guided by investigation to one guided by perception, or from one guided by the intellect to one guided by the body. I used Merleau-Ponty's *"The World of Perception"* as an inspiration to explore this shift. In the first lecture of the book, he debates the value of science versus the value of perception. I used this dichotomy between precision and incomprehensibility to symbolize the breakdown of someone's mind (Merleau-Ponty, 2008).

Thus, various pieces have been layered on, resulting in a random and simultaneous collection of now-incomprehensible symbols; one may see a bird flying around, others may perceive a floating wave or something entirely different. Incidentally, the dissociation has been enhanced because I manipulated these into abstract forms, so they have lost their detailed context. The audience is then left with fragmented pieces of someone's perceptual experience. Amid the chaos, I wanted to allow for moments of reflection where the audience could have a chance to emotionally engage with the subject matter. I did this in each loop occasionally, by calming the complexities, speed, change of colors, variations in size, and transitions. The resulting effect has been unpredictable and emotional ups and downs, shifting the audience's role from an active participant to an observer. The confusion is built irregularly from here, with moments of doubt interspersed with otherwise familiar symbolism.

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Multiple methods and expressions have been used in each group, both thematically and in style. These distinguishing choices were taken to shape the narrative, and to relax the boundaries between the audience and the context. In the first group (Alzheimer's disease), I aimed to extend the possible subjects of the images, get away from depictions of idealized forms or perfect images, and concentrate on the world as it is, imperfect but nonetheless alive in a myriad of ways. I wanted to encapsulate memories that are fallible and fragile. Thematically, I was intrigued by Refik Anadol's *'Latent History'* project (Figure 85,86). He took a non-linear form to explore photographic memories of the past and to reimagine hidden layers of history that otherwise might remain unseen. And aesthetically, I was inspired by Claude Monet's use of light, color palette, spontaneous brushwork (Figure 87), and Alfred Sisley's uncanny ability to capture a peaceful atmosphere.

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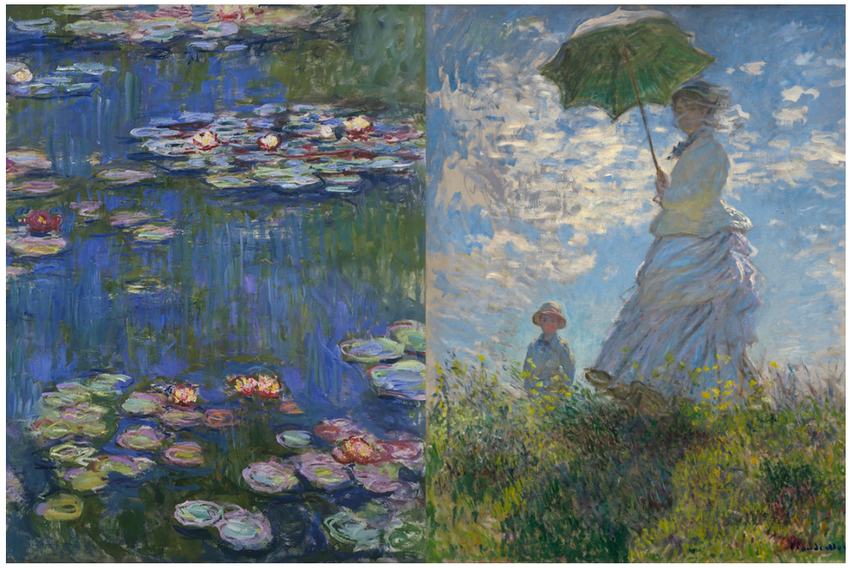

| 85,86 | Refik Anadol (2019). *Latent History* Retrieved from https://refikanadol.com/works/latent-history/
| 87 | Claude Monet (1916, 1875). *Water Lilies, Woman with a Parasol - Madame Monet and Her Son*

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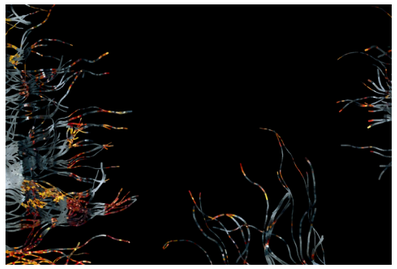

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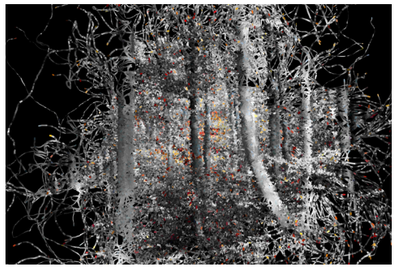

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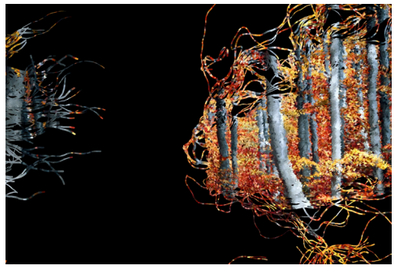

Memories exist as fragmented moments in our imagination, the importance or meaning of which we are actively negotiating in our lives. These scattered moments linger in our consciousness as stories waiting to be told. But how can one decipher these memories? Make sense of them or externalize them? I explored these different questions by using lyrical forms of narrative construction and dream-like visual aesthetics that are both intertwined and disjointed from each other.

Aesthetically, I developed a series of impressionistic brushstrokes. In the first attempts, they created dreamy snapshots, and filled the canvas fully (Figure 88). But I wanted to suggest the moments rather than mimetically representing them. Therefore, I continued to optimize the size, length, and distribution of the strokes, leaving enough room for fragmented representations (Figure 89-91). With this change, while the emergence was representing a growing effect, the illusory aspect of memories and their fragile structures became evident. Through these representations, you can see how one's memory fails to form a complete image due to the progression of Alzheimer's disease, but still embrace its vivid and lively formation.

With the addition of a customized blur filter, the emerging effect has been altered in the final settings. Moreover, this assemblage has been saturated with movement, energy and detail providing a dreamier texture (Figure 92). Consequently, these cloudy fragmentations have created non-linear transitions among the particles.

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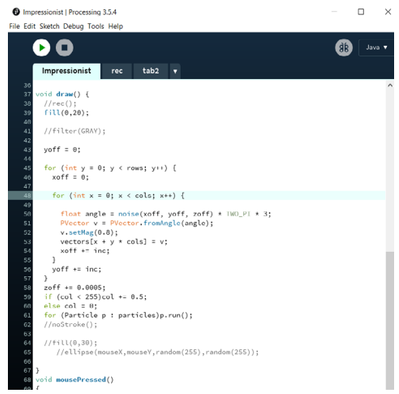

Using these settings, a sequence of moments have been depicted, with no particular time or place. These loose texture serve to point out that memories are often formed in hindsight. Details are lost, hyper focused or distorted and, as a result, a memory is often just a fragment of what may have actually happened. Memories, and the materials we use as reminders, can also be digitally and metaphorically changed, leading to a narrative rather than a concrete definition. (Figure 93). Through these renditions, I wanted to invite the viewer to think beyond the types of things we project onto others.

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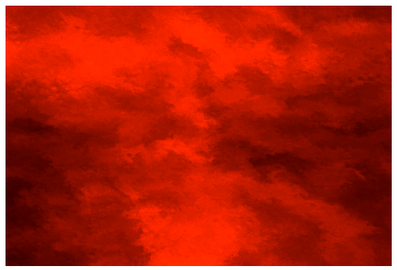

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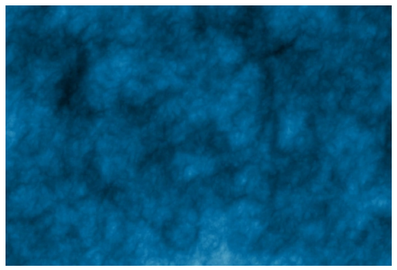

Emotions Expressed in Movement
In the second group (Vascular dementia), I intended to be more expressive, creating emotional ups and downs through abstract transitions and overlapping elements. I wanted to translate the viewer's concentration from one extreme to another, keeping them on the edge, and thus creating an unsettling loop. Initially, I aimed for a clear distinction between the different viewpoints and therefore chose to only use two polarizing alterations – calm and intense tones (Figure 94,95). But during another feedback session with my tutor, it was criticized that these only feature rough transitional phases, glossing over the mid tones. It was suggested to include the inner layers. As a response, I was trying to interpret the mood swings in terms of valence and arousal and subsequently visualized through colors.

Generally, affect is identified by discrete or dimensional emotions. Discrete emotions use basic emotions like joy, fear, and sadness to define the affective state. One commonly accepted method of the last category is identified by James Russell; his circumplex affect model characterizes emotions in two dimensions: valence (pleasure/displeasure) and arousal (Russell, 1980). This model was transformed by a group of researchers to be applicable to affective movements (Lee et al., 2007). They translated the movement characteristics into the affective dimensions: velocity and smoothness (the regularity of a movement). I incorporated their model to design and link the animated pieces to each other. That means on the positive side, the animated elements make much more harmonious, smoother movements, while on the negative side, the movements entail more disharmony and are jerkier and harder in their appearance.

These movement patterns have been linked to Itten's circular color model (Itten, 1969) and Itten's color system, in its turn, has been adjusted to fit Russell's circumplex model of affect. I applied Itten's transformed color circle, in combination with the emotion-movement relation framework, as a basis for the animation design. Both were merged into one model, as is depicted in (Figure 96).

Using these adjustments, the layers have emerged and dissolved unpredictably, shifting from irritating and unsettling to peaceful and calming, adding to the degree of confusion and emotional arousal (Figure 97).

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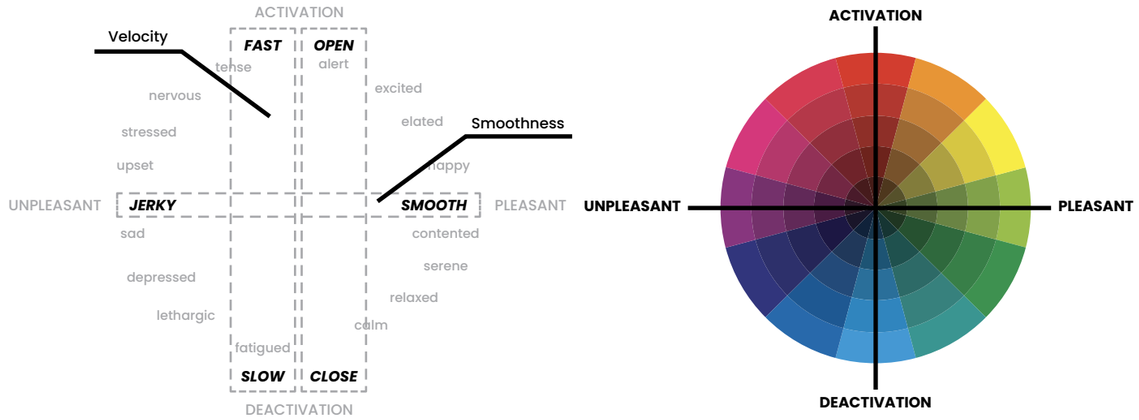

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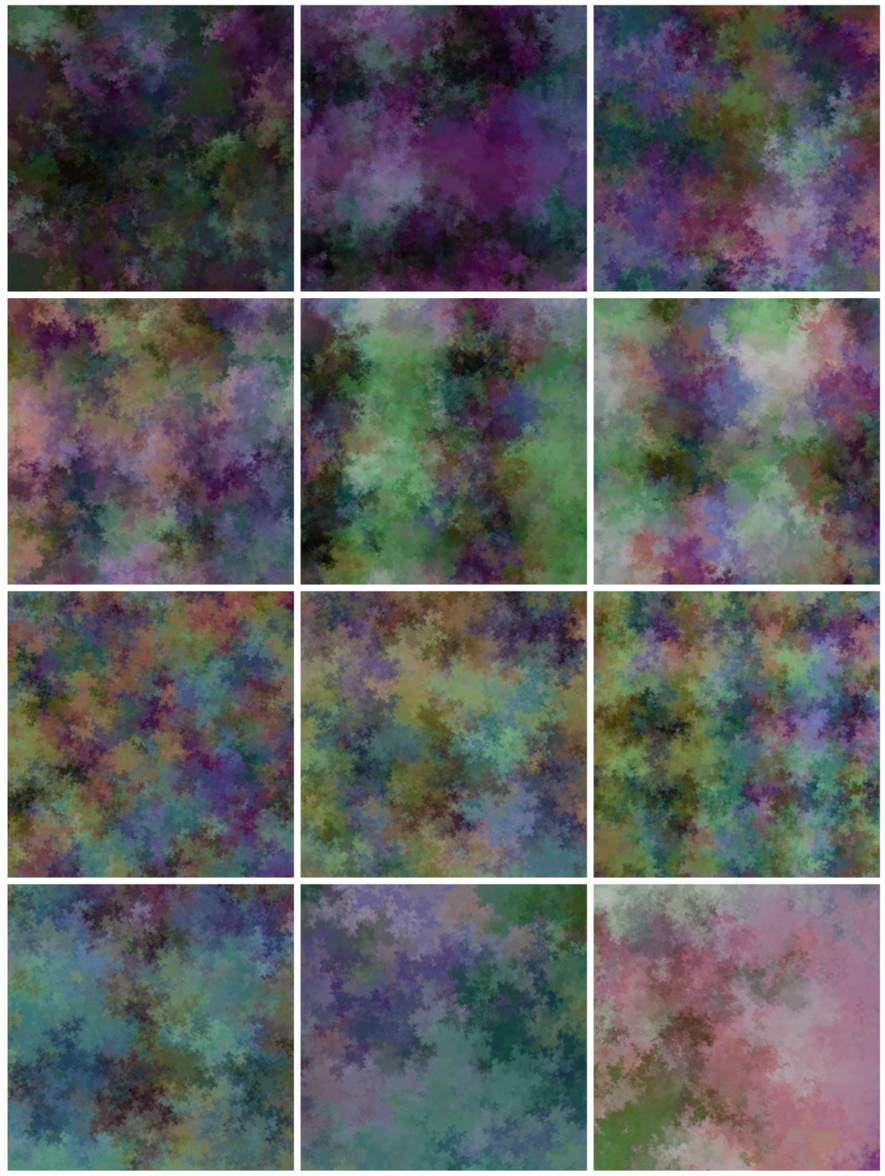

Concurrently, a series of overlapping transitions has been created, juxtaposed with recognizable samples of animated leaves, trees, texts, waves, and human hands (Figure 98). These have been assembled to validate the feelings of worry, anxiety, tension and becoming lost. Once a transitional piece is revealed, the audience's attention turns to familiar elements, but not so long after, it turns back into unfamiliar and overwhelming waves of uncertainty. This combination of abstract and symbolic layers suggests different emotions, allowing room for reflection.

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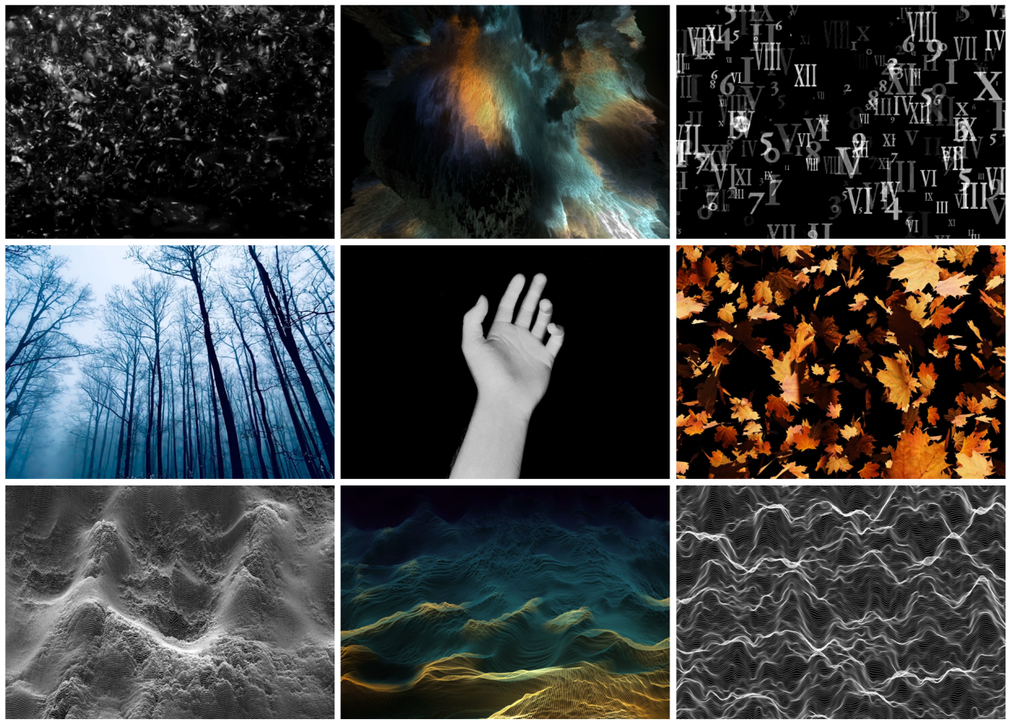

Warped Reality

As dementia advances in the minds of people who have Lewy body dementia, their perceptions warp and, unfortunately, misinform. They see, hear, and feel things that are not quite there. This miswiring can manifest in three ways: illusions, hallucinations, and delusions. With illusions, an object is physically there, but it is seen as something else. For example, one might see a person in the corner instead of a coat tree. Hallucinations are misperceptions of objects or events affecting the senses. They seem real to the person experiencing them but cannot be confirmed by anyone else, they are false perceptions resulting in either positive or negative experiences. Delusions are fixed, false ideas that form in the brain and cannot be reasoned with, in which people who have dementia think someone close to them is an imposter, acting in bad faith, or conspiring.

Evidently, imitating delusions in visual form is impossible since they are defined as beliefs that conflict with reality. Hence, in the last group, the focus has been shifted to depict hallucinations and illusions often associated with Lewy body dementia. Additionally, other common symptoms like slowness, and navigation problems have been highlighted. To visually depict these, several mixed methods and applications like Cinema4D, P5js, and Processing have been used. First, I gathered a list including the most typical forms of hallucinatory experiences like seeing flashing lights, colorful images of animals, human figures, birds, and elaborated scenes resembling dreams among people who have this form of dementia. Then, a sequence of animated birds, fishes, words, and lights together with a few kaleidoscope transitions have been made to illustrate hallucinations and optical illusions (Figure 99).

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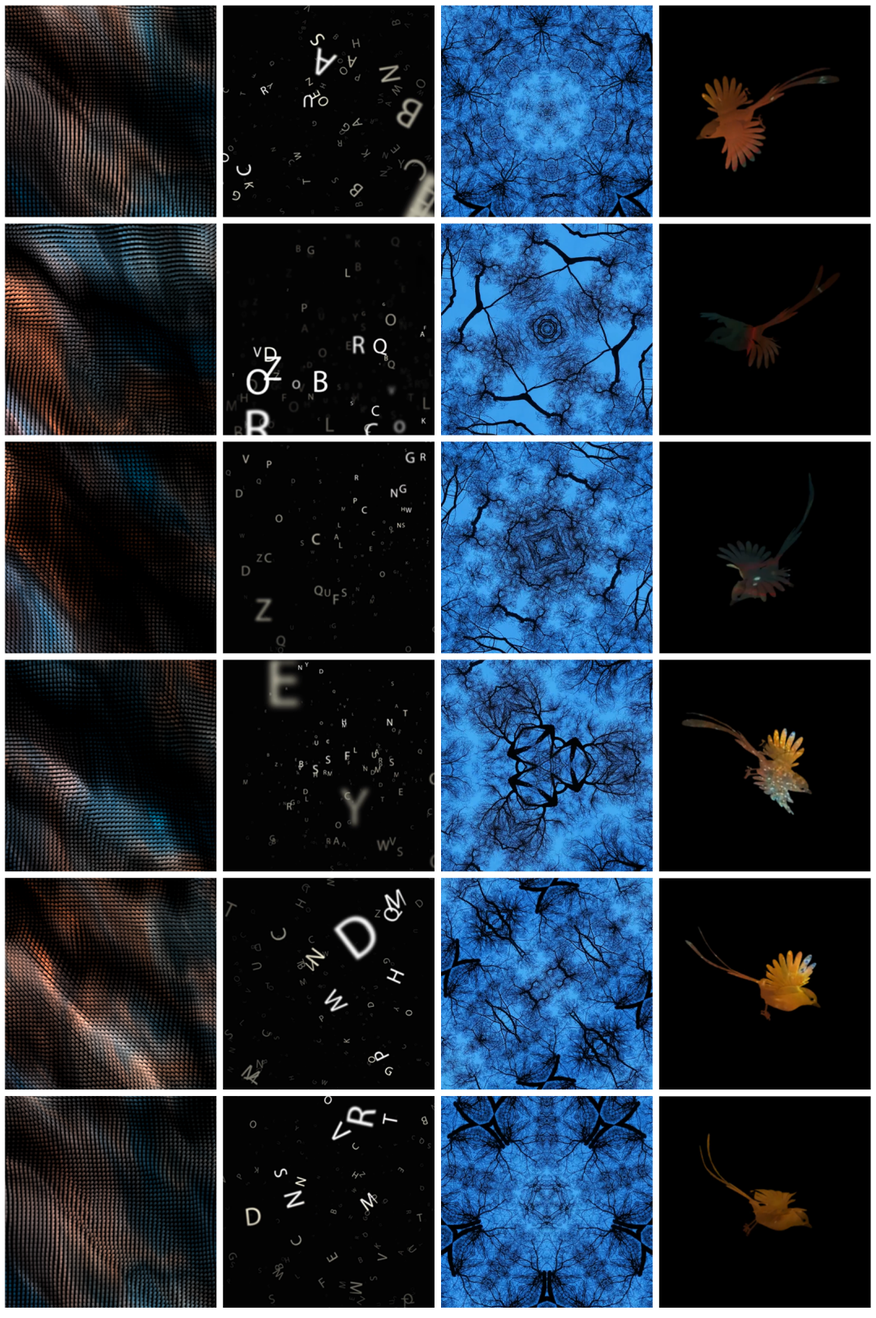

I tried to warp and distort the mood in these sequences. My intention with these distortions was to show that hallucinations are vivid, at times stressful but seldom scary. It was important to make sure the content was not overdramatic or scary but informative. Hence, while the lines and figures were chaotic, the color palette and the pace were predominantly mellow. Furthermore, hallucinatory figures complemented visual abstraction that were especially oblique and amorphous. Their overall outcome was dreamy delirium, created by editing which largely disregards spatial and temporal unity, with unconventional compositions. This combination has resulted in triggering either relaxing or overwhelming feelings (Figure 100).

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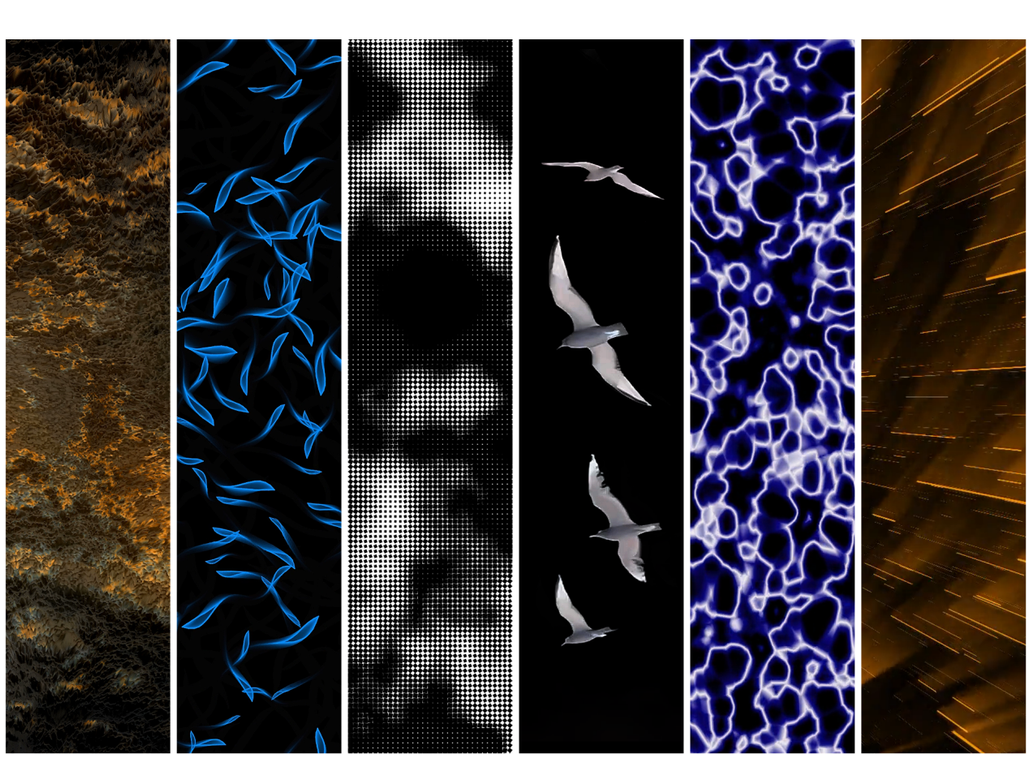

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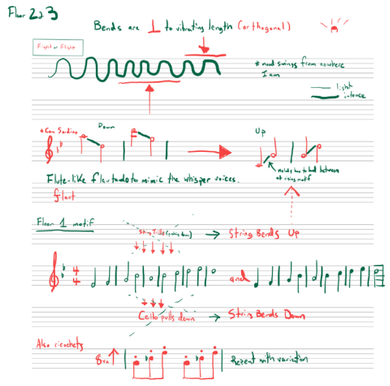

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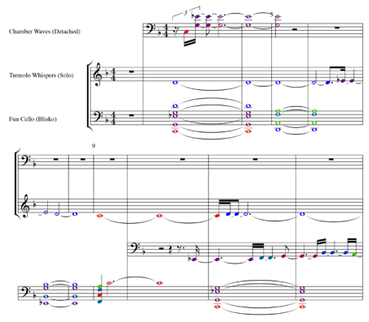

Soundtrack

To enhance the visual content, a soundtrack including three distinct tracks has been created. This inclusion has been developed in collaboration with a modern classical composer from Seattle, Kyle Preston. From the outset, it was very important to me to engage Kyle in a very pure creative process. What I wrote to get him started was some keywords and short descriptions to describe the visual content mixed with some aesthetic choices without any indications as to theme or scale, just to free him up from that. Through many conversations with him over the course of the last calendar year, many shared notes and drafts have been outlined, providing a blueprint for the soundtrack fitting the visual content (Figure 101). In those outlines, we emphasized the tone and atmosphere over traditional musical structure.

Part of the process was to start fresh, to come up with a new palette. It was essential to feel human presence in the music, to keep the experience about not just the space that we are looking at, but the people in that space. And to achieve a dream-like quality that the visuals have but prevent the audience from identifying where the music ends, and the world begins. When he played me the piece of music which became the basis for the entire score, I thought it was perfect and captured the emotional qualities in the experience I wanted. What that did to Kyle was it set him very firmly in a direction relating to the heart of the project. After a lot of hand sampled demos, we decided on the first track. In that track (Figure 102), a ricocheting effect was created to crescendo the emotional picks and prevent the notes from reaching to the highest points. In addition, the octaves have been moved wherever

needed, allowing the other sounds to fill the gaps in between. While several string trills have been added to create tension, the climactic choral music elevated the piece immensely. That blend has resulted in an emotional, harmonious melody.

In the second piece, we took a different approach. We wanted to create an unsettling, alarming atmosphere. Thus, tension was built up and released throughout the track by the addition and subtraction of layers of instrumentation. In the intro, a floating sound fades in, immediately blends into a wave of alarming sounds including sirens, whispers and what hints at some hands clapping. As the music progresses, these speedily played transitions sit atop the foundation of the track, pushing the melody to the background. Even though many of the effects may seem very cyclical within a given moment, focus is never lost on where the song is moving next, like in the ending section where suddenly, an entirely different chord introduces itself, ringing along with the violin notes for beautiful harmony. To create these warmer, more harmonic effects, and to achieve an aching quality, we used flautando (flute-like) sounds. This allowed us to add a breathing, specious texture on top of overlapping compositions. Thus, it is hard not to get wrapped up in the track, get lost in it since the chords and notes cascade over one another with a little bit of delay. The execution is fast, somewhat technical as well, but the music that is being played is so in the moment and purposefully straightforward (Figure 103).

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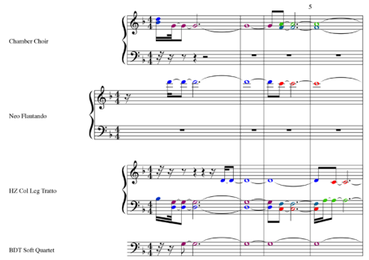
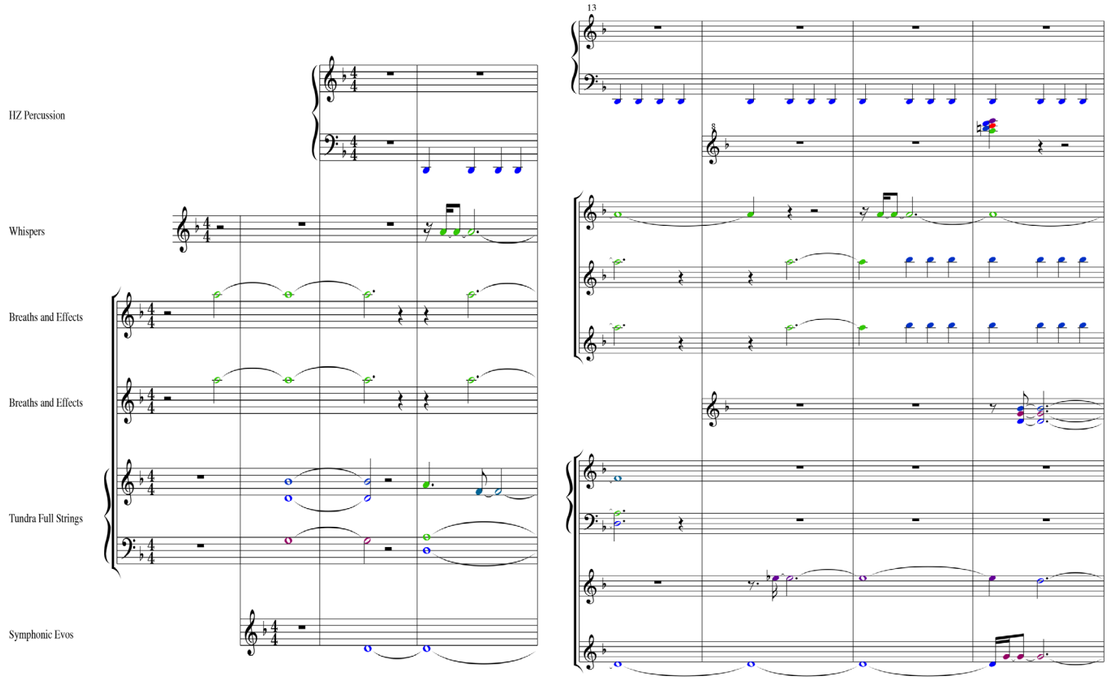


These compositions are displayed in (Figure 104); the jagged data lines on the bottom are all the different dynamic layers that have been added to all the instruments. The bars above are the actual notes and the colors correspond to their 'velocities', i.e. how loud each note is (cool colors are lower velocities indicating softer, more delicate notes – warmer colors are higher and louder).

| 104 |

In the last piece, we focused on the echoing effects and compositions to create an indefinite hallucinatory piece. The emphasis on reverb accomplishes a few things; as essayist Andrew Stiller noted, *"Heavy reverb, because it implies a huge, enclosed, hard-surfaced space, creates a mood of mystery and paranoia"*. It also gives a feeling of distance to everything, as if the audio is coming from far away, like in a dream. Finally, reverberation blends things together. This was one of the crucial ways Kyle folded separate audio sources into one aural master track. Every sequence was composed to create a cohesive acoustic environment. Occasionally, the emphasis was on the aesthetics or sound effects, other times it was on the emotions (Figure 105).

All of these disparate textures have been stringed together with appropriate musical themes fitting the visual content. Therefore, when the music swirls, it is as if it is coming from within the visuals themselves, like a release. These spontaneous, first-tape compositions have resulted in a deeply personal reaction to the visuals, a second vision that fuses with my own.



4.4.5. Virtual reality

Developing content for Virtual Reality (VR) involves several workflow adjustments to ensure that the user gets the best experience possible. When a user enters virtual space and the physical world falls away, immersive technology takes on a responsibility to build trust with the user while still delivering a compelling experience. This dynamic relationship encourages designers to think more broadly about the communication between the user and the virtual environment.

Though the whole process of making a virtual reality experience was something new to me, and there was much more to be defined in a rapidly evolving space, using a proper framework was helpful in ensuring that the emerging immersive experience was both compelling and novel. Thus, to ease into the process, an early user journey was crafted which highlightes the interaction and general layout (Figure 106). The main intention with that was to focus on immersive storytelling techniques and to avoid gamification mechanisms as much as possible. In the following section, I have tried to provide a detailed description of the framework that I have used for mapping the VR experience and the design strategies that have been considered throughout.

Using Unreal Engine, I built a new project and used a virtual reality template inside the application. This template included two maps, displaying the functions of the VR and how a user can interact with some 3D elements in the environment. In addition, it featured teleport locomotion, letting the players move around using motion controllers. Next, I needed to figure out the optimal settings.

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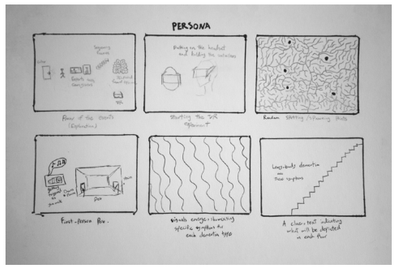

Settings

The first and perhaps the most important aspect in building a virtual reality experience is to start off with the proper setup. Most VR applications use their own procedures to control the frame rate. Therefore, several general UE4 project settings that can interfere with VR applications have been disabled. Starting with the project settings, many heavy processing functions like Smooth Frame Rate, Use Fixed Frame Rate have been unchecked. Next, under the rendering tab, instanced stereo has been checked on (this has to do with how many passes are rendered for producing content in VR). Continuing in the same tab, Anti-Aliasing Method has been changed to MSAA. These early settings changed the performance immensely and led to a higher framerate (Figure 107). Following that, ensuring the proper scale of the environment was essential to help deliver the best user experience possible on VR platforms. Having the wrong scale could lead to all kinds of sensory problems for users. To achieve the ideal settings, I adjusted the World to Meters value; a wrong scale would have made the world appear to be very big or small.

Finally, to avoid simulation sickness, some major adjustments have been implemented: cinematic cameras or anything that takes control of camera movements away from the user were avoided, allowing the audience fully to control their movement. Moreover, dimmer lights and colors were used since strong and vibrant lighting in VR can cause simulation sickness to occur more quickly. Depth of field, motion blur, bloom, and lens flares post processes were not utilized as well, because they can greatly affect what the user sees and, more importantly, they can lead to simulation sickness.

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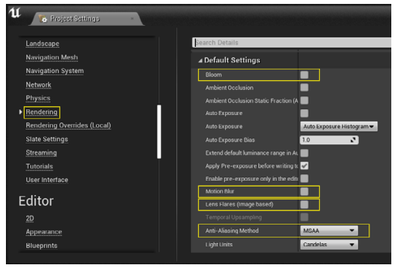

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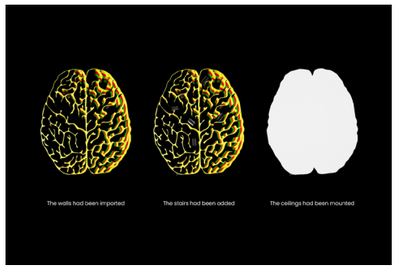

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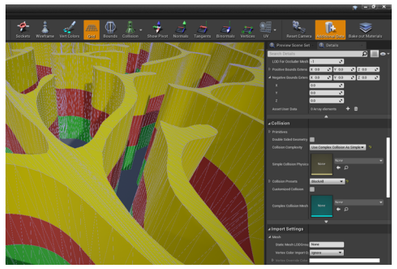

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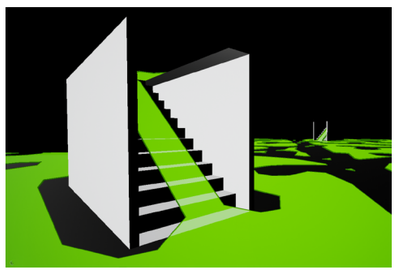

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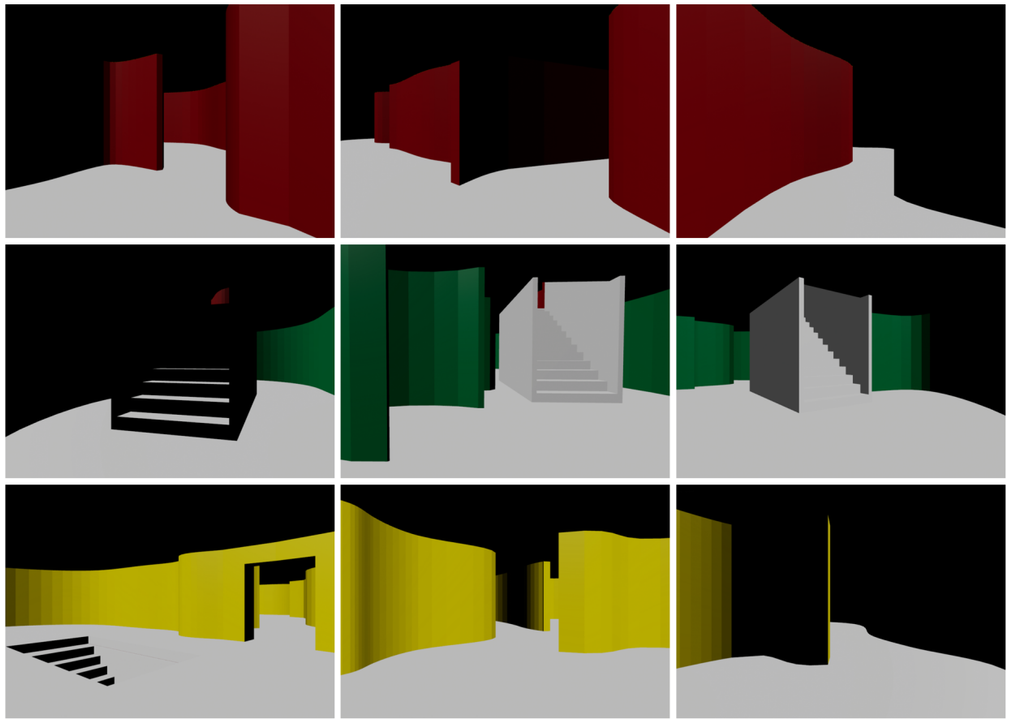
Navigation and Collisions
Once the initial setup was finished, the 3D elements of the maze (walls, stairs, ceilings) have been imported as static meshes inside a new level (Figure 108). Then, I ensured that these elements were in the same location and were sharing the same scale and orientation. The assemblage of these assets shaped a whole 3D model of the maze. Subsequently, any excessive casting shadows have been unchecked to avoid heavy lighting processing. Through camera movements, I was able to maneuver around the environment, check all sections of the model for necessary adjustments.

To avoid any falls or overlap with the walls and surfaces, and to add physics to the environment, collision traces have been used (Figure 109). A collision trace creates a map around a desired place and implements physics in that particular space. Since all the assets were static meshes and had different edges, a customized collision system was needed. Therefore, the collision complexity was changed to complex, allowing the vertices to be retraced in detail. This has been accompanied by a blocking collision preset that prevents the users from any overlaps with the surfaces. The same pattern has been applied to the stairs and ceilings as well. Once the collisions have been added, a navigation mesh volume has been created covering the entire surface of the meshes (Figure 110). Since certain areas were not accessible or had very limited area to land on, the RecastNavMesh settings have been readjusted for proper teleportation (Figure 111).

To determine where the character was in the world, I needed to have a player start actor located in the environment. Then, I had to make sure the engine automatically registers that actor to receive input from the user and spawn the actor in the desired location, regardless of collisions. Afterwards, I needed to make a new game mode so the engine would know who the character was and where it was. And to create random spawn positions, several player start instances have been made and positioned around the floors *(each floor contains multiple player start actors)* (Figure 112).

| 112 |

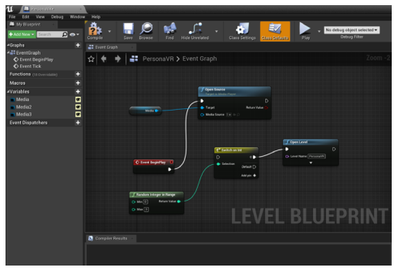


Blueprints

To initiate the interaction, I used blueprints. The blueprints visual scripting system is extremely versatile and efficient, allowing to use virtually the full range of concepts and tools typically only available to programmers. To take advantage of that system, and to add more complexity to the experience, I built and expanded several blueprints. Using blueprints, several nodes that shuffle the player positions while loading the targeted level have been made (Figure 113). That randomness added another twist, and created a unique initial experience for each interaction.

Next, I explored the environment with the VR equipment (Oculus Rift). When I was passing through different locations, I noticed some teleportation issues. Occasionally, the teleportation beam was not working properly, particularly near the walls or navigation boundaries. In those cases, the landing area was getting attached to the other floors, teleporting the character to the opposite floor either above the wall or below it. To fix that issue, I needed to understand how the teleportation system works. So, I started digging into the motion controller blueprints. I understood that the Trace Teleport Destination function in the MotionController blueprint projects the hit point onto the nav mesh (Figure 114). By default, a single float-Project Nav Extents is used for the distance in all three axes. Furthermore, nav mesh does not follow normal geometry exactly, so it needs a projection tolerance but nothing as large as 500, which is the default value. In fact, 500 was likely larger than the distance between floors, so it easily pick a nav mesh point on the "wrong" floor. By lowering that value to 100, accidental picks have been avoided (Figure 113).

| 113 |



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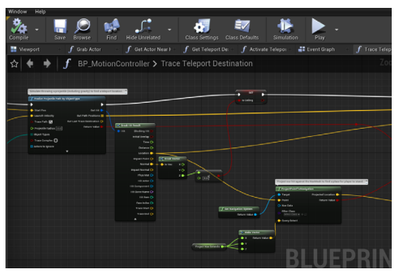

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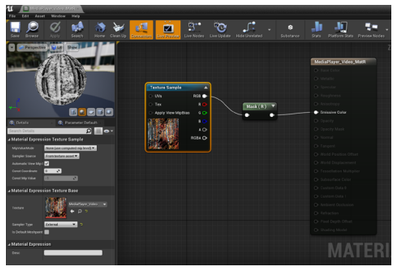

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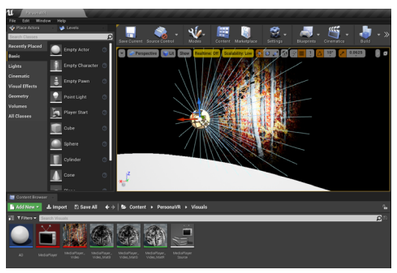


For finer control, I had to keep a wider tolerance aside from height. So, inside the same blueprint, the Break Hit Result node has been broken into floats. Then, I checked for the Z value to be positive and created a boolean variable to cover the negative aspect. So, if the value was negative, it would point downwards, avoiding teleportation. I also checked if the beam was grabbing the ceiling points, so the teleporter had to be disabled. These changes helped in fine-tuning the teleportation trace, avoiding it from going above certain heights.

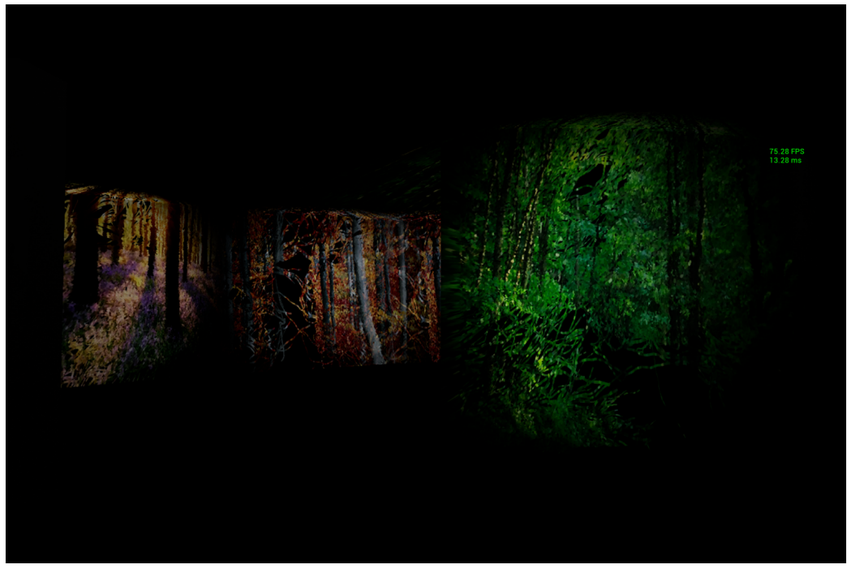
Visual Mapping

To map the visual content onto the walls and surfaces, several media assets were required. First, a media source was created linking the source of the media to a local path in the computer. Then, a media player was added, and the same source was put on a loop. Afterwards, a media texture has been associated the media player with the texture. And finally, from the same media texture, a material was created (Figure 115). That texture worked fine on flat surfaces, simulating projection. However, the intention was to project the content onto trusses and not flat surfaces, thus more detailed adjustments were required.

Initially, another blueprint actor has been made. Then, three spotlight components were added and parented together. Next, I duplicate the media texture material multiple times. Inside those, only the red, green and blue channels were pulled from the texture. Afterwards, each light function has been applied to the corresponding colored light. Thus, when they overlapped each other, the RGB color range of the media texture was made and the proper color of the projected light was visible (Figure 116).

Following the same pattern, from these assets, three variations have been made for all the floors. Then, I scattered several projections of each type around the first floor. Using multiple media textures simultaneously had caused a huge performance drop, because each instance included three dynamic lights and three video textures (Figure 117). Moreover, in order to cover the entire maze, massive GPU calculations were required. To reach a stable framerate, the number of instances and calculations had to be reduced. To do that, only a section of the maze, and level streaming have been used. Once a smaller chunk of the model was reimported, each floor has been covered with its corresponding visual content (Figure 118). With that alteration, the layers were ready for level streaming; the first floor illustrates the Alzheimer's disease symptoms, the second floor indicates Vascular dementia, and the third floor dementia depicts dementia with Lewy bodies (Figure 119).

| 117 |



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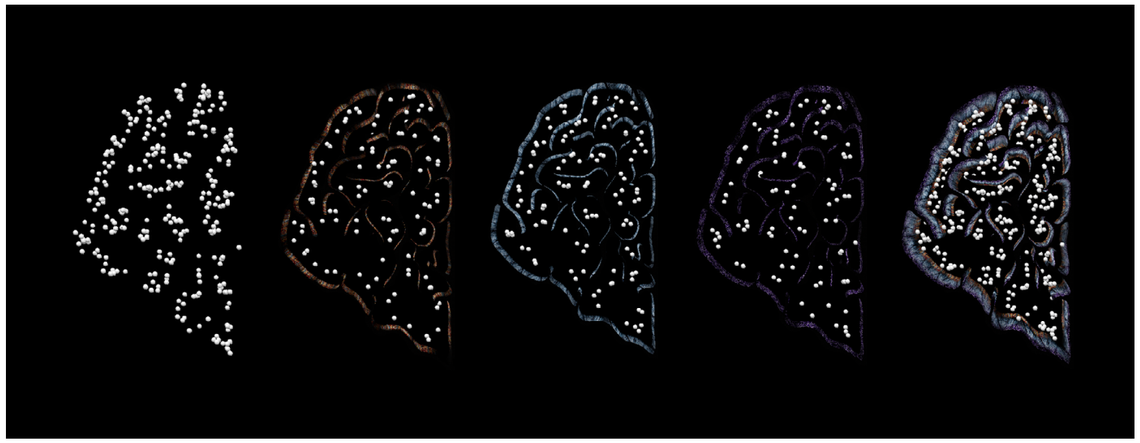

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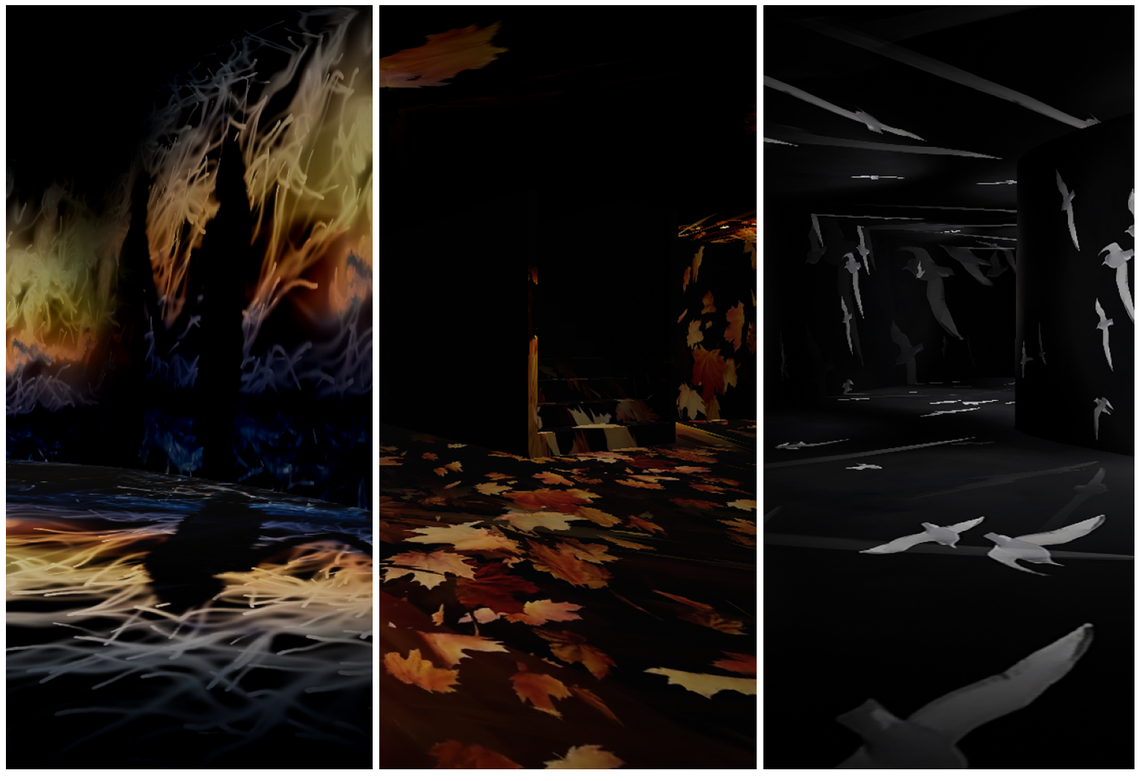
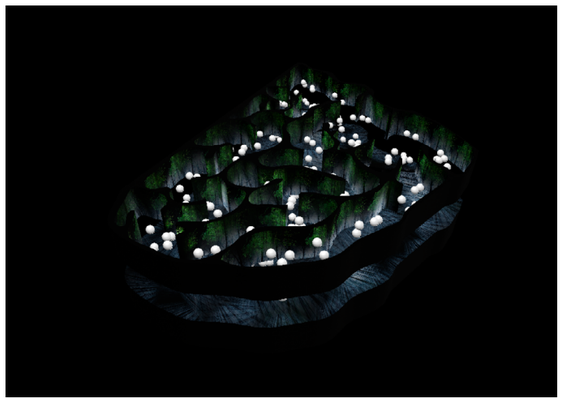


Level Streaming

In another discussion with my tutor, I expressed the possibility of using level streaming to separate and load a massive environment. That way, I could efficiently load the content and avoid costly GPU performances. So, I started experimenting with the layers and level details. The first step in getting the levels to blend together was adding sublevels to the main level. Then, I separated everything that had to be always loaded and streamed in the space (e.g. stairs, player pawns, nav mesh, level streams) and layers that had to be loaded using blueprints (e.g. walls, ceilings, audiovisual content). After that, three level streaming volumes were added to the main level and had been tied to their sublevels. Level streaming made it possible to load or offload maps into memory, in addition to toggling their visibility during play. Since the space was broken up into smaller chunks (Figure 120,121), only the relevant parts of the world were taking up resources and were being rendered at any point. That division hugely improved the performance, and led to a stable framerate in the VR experience.

| 120 |



| 121 |

User Testings

As with any other forms of research and testing, it was important to test the application with real users to ensure the experience works and to get the best results. This user study had 11 people participating. The number was deemed to be adequate as it has been shown that a total of 5 to 8 participants can expose about 80% of usability problems through user testing (Nielsen & Landauer, 1993). As usability testing was a part of my user experience evaluation, 11 participants, including several caregivers and designers, were enough to produce qualitative and quantitative data for this experiment. This process involved several ethical and technical procedures. At first, it was essential to give an overview of the experience, describe how they can interact with the VR equipment and what may be seen in the environment. I also made sure that they read the health and safety guidelines, to see if they feel comfortable starting the experience. It was also stated that they could take a break at any time.

Facilitation is proven to be harder in VR because the user experiences an entirely constructed physical environment different from the context of the interviewer. As an interviewer, I could not simultaneously immerse myself in the environment, and a disembodied "interviewer" voice from outside could ruin the experience. Therefore, any interruptions or unnecessary questions during the play have been avoided. Considering this, I left enough preparation time for users to get familiar with the technology, headsets, and surroundings. It was necessary to let them practice a few minutes before they could dive into the "other world". I also tried to help them feel safe throughout the experience.

Once they were finished, enough time was given to participants to reflect on what they had seen. And I made sure they feel fine, then I started asking more questions. Those questions were divided in three categories: the context, the experience, and its usability. The first group of questions were focused on dementia, and the participant's knowledge and experience about the disease. The second group of questions were centered around their feelings towards the experience, and in particular phases, it was to see what the content represented to them, if they found them fitting each other or they felt they were not in sync. It was also to see what was working in terms of interaction, and what was lacking. And the final questions were to explore the application usability and what it can contribute to.

Almost all the participants were willing to share their feedback. Their thoughts unveiled new perspectives and understanding about dementia care, and the experience usability. To reveal a portion of the conversations, and to illuminate their insightful perspectives, a few examples have been selected here.

| 122 |

Ine, a master student in molecular biology who worked as a caregiver before, was one of the participants (Figure 122). She talked about her background, nursing homes situation, how she felt about the VR experience and how it could be used for educational purposes and raising awareness about dementia:

"At the section I worked there were all kind of patients from elderly people to dementia patients. But we only had a general understanding of the disease. For example, because they were forgetting things, they felt either sad, frustrated, or shy. So, many of them were trying to hide

their feelings. There were also a lot of mood swings, and hallucinations in forms of humans, animals, and seeing patterns."

During the conversation she emphasized on the lack of educational plans for the caregivers in nursing homes:

"Unfortunately, it was all experience. I started when I was 17 as a summer job, and I was basically thrown in the environment without any previous knowledge. What surprised me the most was that often they didn't tell the history of a patient, so you really had to do the work yourself, looking at the journals, speaking with people, getting yourself familiar through experience."

She described her feelings about the experience:

"Because there were a lot of walls and rooms around, I felt lost and confused of my whereabouts. The second floor was more stressful than the other floors since it had brighter colors and needed more processing. The third floor was more meditative and hallucinatory, it was the place that I was going back to a few times. I recognized symbols like hands, leaves, birds, and letters in the environment, each were giving a different feeling to me. Because the images were blending together, some were calming, and the others were making me anxious to leave that area."

And finally gave her opinion about how this experience can be used to improve caregivers understanding about dementia:

"Absolutely, I remember often that my coworkers and I were saying, I wonder how it's like in their brain, because they say that I'm seeing this or that, it would be interesting to see what is actually happening to them

or what they are seeing. I remember a woman who had Alzheimer's disease was touching the walls, looking around seemed very curious about something that I couldn't see or feel. I feel an experience like this brings that understanding about some of these examples."

| 123 |

Monica, a master student in design, was one of the other participants (Figure 123). She did not have any prior knowledge or experience of dementia types, only knew a bit about Alzheimer's disease. Therefore, her thoughts were centered around the interaction and the overall experience:

"The initial feeling that I got from putting the headset on and getting immersed into the virtual reality was great. For someone who isn't used to this technology, those first moments really 'hook' you, and make you curious to see more. The interaction was simple enough to understand and control."

She also expressed her feelings towards the experience, and how each floor made her think:

"Because the maze looked the same in every corner, it was easy to get lost and I couldn't remember if I had been in the same space before or not, but I believe that feeling connects to the overall feeling of people who have dementia."

"The music greatly heightened the overall experience and really fit the simulation and graphics that were being displayed on each floor. The first floor made me think of memories, because of the images that appeared and faded away in a thread-like animation. I also got a feeling of hope; maybe because of the colors and the symbols that appeared. The dotted or impressionistic painting style added a dreamlike quality to the experience.

I remember entering the second floor to a dark, red room, which is instantly not welcoming. It doesn't make you feel at ease and it is somewhat invasive. I recall seeing different colors, going from darker tones to more calm ones, and the graphics matched those feelings. For instance, for the dark tones, I recall seeing abstract spikes and more abrupt music, and it subtly changed to a calmer nicer melody. And lastly, the third floor is the one I remember the most. It gave me this sort of feeling of deathlike peace…Maybe like someone who is in the later stages of life and is at peace with life. The mosaics and colored patterns made me think of hallucinations. And I remember symbols such as birds flying, trees and abstract-like fishes which made me feel more emotional too."

| 124 |

Marte, another master student in design, who also worked as a caregiver, expressed that she felt a bit lost and unsure about where to go at first, but once she had been there for a bit, felt confident enough to move around (Figure 124). She talked about her previous background as a caregiver and then stated how this experience provided a new perspective about the disease for her:

"I have worked with people who have dementia before, and I found the experience made me able to empathize with them in a new way. The confusion, something familiar that you can't get a grip on, and struggling to make sense of space and time was something that I felt for the first time."

She also described her feelings towards the VR experience as:

"The VR experience was intense and immersive. I could feel the effect of the visuals and music on my body. The first floor that I went to felt unstable. Calm and beautiful

at some points, stressful and confusing at others. To me, the music amplified the experience, and the spatial qualities did the same. The music and the visuals seemed to fit together. The second floor I went to mostly felt peaceful to me, like I was being lulled into a numb, but comfortable sleep. The visuals spoke to me in different ways. The more abstract ones made me feel comfortable and calm, whilst the ones that had numbers or words were stressful. Some visuals blurred the line between the floor, walls, and ceiling, and made it hard to find my footing. These types of visuals made me want to grab something for support. They featured trees, something that I normally find comforting, but their movement made me unsure and uneasy."

She stated her feelings towards the application usability as:

"I think it is useful for people who work with dementia patients to go through this experience, because it is so physical. You can feel your heart rate change based on the experience, and the feelings of comfort or discomfort are very real. Because people who don't have dementia have never experienced what it is like, it is hard to understand. For more patience, understanding and empathy, this is an experience I hope many people will have."

The biggest takeaway from these interviews was the emotional response among the participants. The possibility to learn through the lens of their experience was so rewarding and necessary in preparing for the best experience. It was surprising to hear so many detailed and diverse reactions, covering many aspects of the experience, from the interaction to the context and beyond. In terms of interaction, they shared a similar pattern; they felt they became more familiar with the controls after the initial introductory phase. As a result, their experience improved automatically.

In their feedback, they expressed that your position in time and circumstances colors your telling of a tale. Even though, those circumstances may lead to distress or frustration. Moreover, they expressed the pace and progression of the audiovisual content were inducing different emotional responses, and the model's mazy atmosphere was adding to the psychological pressure and confusion in the environment. But above all, they felt this immersive experience provided a new perspective about the disease by illustrating the other symptoms that many were not familiar with and made them empathize with people who have dementia in a new way.

Output
Finally, multiple steps have been performed during the packaging and distribution process. Firstly, project-specific source code has been compiled. Then, all required content have been converted, or "cooked" into a format that can be used by the target platform. Subsequently, the compiled code and cooked content have been bundled into a distributable collection of files, such as an installer. Therefore, the VR application is ready to use on systems running Microsoft Windows64-bit versions equipped with Oculus Rift or HTC Vive. This packaging process ensures all the content and blueprints are up to date and in the standard format to run on the preferred target platform.

To provide a glimpse of the experience, a couple of examples have been captured from the application in real-time; the human models are merely visible in these examples to visualize the experience and its immersiveness (Figure 125,126).

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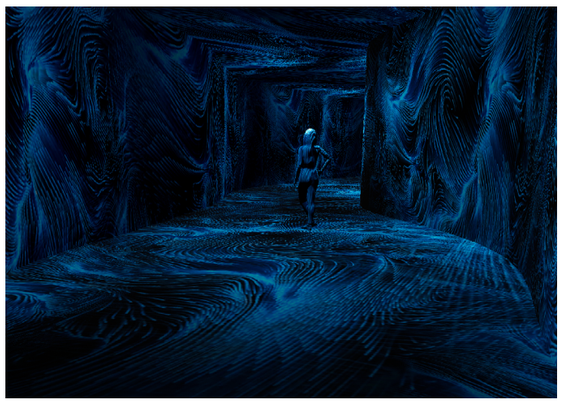
| 126 |



4.4.6. The exhibition concept

Based on the context of my research study and visual process, I sat on the following concept for the final exhibition.

Summary and Background
As I explained at length above, dementia affects the people who have the disease, as well as their relatives and other caregivers, who have to cope with watching a family member or friend get ill and decline, while responding to their needs, such as dependency and behavioral changes. It also affects the wider society because people who have dementia also need social and health care. Despite rising awareness of dementia, understanding of the disease is low and dementia is often considered to be a natural part of aging. The lack of awareness leads to fears about developing dementia and induces stigmatizing attitudes such as prevention or discrimination. Stigma and misunderstanding can have a detrimental effect on all stages of a person's journey through dementia, thus indicating the need for urgent action to reduce stigma and to improve the level of understanding across all areas of society and, in particular, among the caregivers. To counter this problem, I chose immersive storytelling and virtual reality to raise awareness about dementia and its complex nature, and to provide a postive outlook with the following idea.

Focus, core idea
'Persona' is a multisensory experience that illustrates wide-ranging layers of dementia to its audience. In an enclosed room, the audience is invited on a poetic journey that examines the fragility of the human mind. The pieces around the room deconstruct the audience's conception of the disease, raising universal, and metaphysical questions.

Each visitor views the experience through a different lens, depending on how and in which way they choose to interact with the pieces. While roaming the room, visitors may decide to reflect on a particular piece more than the others if they feel intrigued or emotionally engaged in it. Upon entering or leaving the exhibition, visitors may uncover and relate to the narrative concealed behind each piece, or build one of their own. These choices will determine their experience.

Objective, intent
My intention with this project was not to define the disease or generalize its multitude of symptoms but to share a more inclusive vision of dementia among the caregivers and public. I believe general solutions presented out of the frequently misinterpreted position of designers as enablers, accelerators or reinforcers of the current healthcare system have often caused more harm than good. Conversely, I would like to use visual communication to create an immersive experience that improves understanding of the problem, makes it visible, and communicates knowledge to an audience that in turn can initiate change in their own professional fields. I rather aim to enhance peoples' perception of the disease instead of providing them with a new tool that solves their problems. I want to encourage the audience to reflect upon the similarities and differences that are shared among us and people who have dementia, to see that we are all human. Derived from that, I want the audience to realize that their understanding may not be identical to the perspective of people who have dementia about the same issue. This project aims to leave a spark rather than a fear about dementia and a focus on how we can actually enable a more human, accessible, knowledgeable, and connected world.

Target audience
Due to the widespread effects of dementia on caregivers, families and society at large, the problem of my thesis concerns almost everybody, making it difficult to define a specific target group. The knowledge that I want to convey to my audience can be categorized as general knowledge, which means it is something everyone should know or be aware of. I will therefore not define my target audience with specific demographics. Instead, I will describe groups of people who can help my cause to different degrees or can benefit from it the most and, in that way, define my own audience.

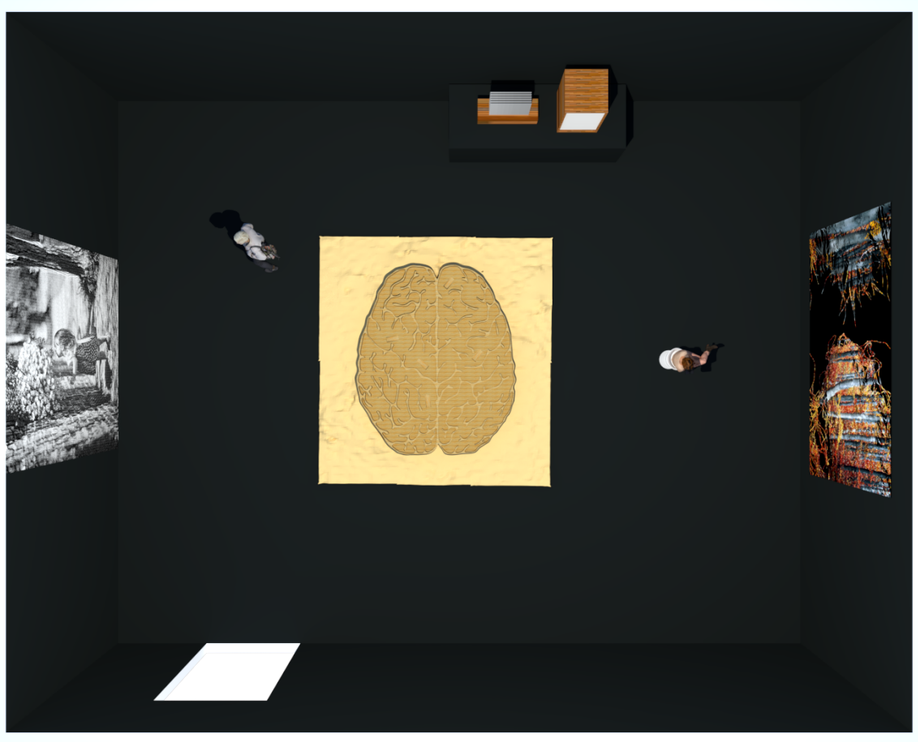
The project's primary target audience includes informal caregivers who are new to caregiving, or those who have been caring for someone further into their disease process. New caregivers may want to understand what they are getting into, and more experienced caregivers may have realized there is a lot more to it than they had first expected. Moving on to my secondary target group, managers and other executives in the field of health, dementia, healthcare community leaders and representatives who hold great responsibilities as their everyday decisions impact the lives of people who are dealing with dementia. This group is also made up of people and professionals who discover facts, generate knowledge, and communicate it to the general public like journalists, activists, the academic milieu including students and researchers, and the artistic milieu including designers, artists, writers and filmmakers. I want to trigger this group to become aware of the scope and variations of the disease and be more proactive, spread the word, discuss with their peers.

To sum up, my primary target group includes people who are dealing with dementia care, experts in the field who hold executive powers and those who generate knowledge and know-how, but would benefit from the communicative and transformative power of a design project like mine to give these findings a broader platform. I am aware that our graduation show will attract a certain, limited audience. It will mainly include friends, students and employees at KMD and designers from local design studios. I will do my best to expand this reach and intend to reach my target audience specifically through invitations to the exhibition and in the future individual exhibitions of the project.

Visual language
At the time of writing this thesis, I was still making minor adjustments to the visual language of the exhibition model. So what I describe here only gives broad guidelines of which not all have been tested yet. As I want to create a multisensory experience that evokes various emotions, I am testing and combining traditional aesthetic choices that may fit the pieces while at the same time finding a new aesthetic and identity from these combinations. My main focus is to bring each piece to life and create a lasting effect that not only grabs the audience's attention but it touches their heart. The scattered pieces around the room will resemble a fragmententation that matches the tone and the context of the project, so as the audience roams around, experiences with and reflects on the pieces, a more coherent narrative will emerge that underlines the merging of the pieces within my project. The other stylistic decisions will be determined in the upcoming documentation phase of the pieces in the room with the materials and technical equipment.

Budget, resources and implementation
I had to mostly rely on resources provided by the school since my project budget was very limited (1500 nok). The exhibition was intended to be held in room 206, which is one of the project rooms right besides the main exhibition area of the Master in design graduation show at KMD. However, due to the new COVID-19 restrictions and the extreme circumstances, our final exhibition will be held online. To present the project pieces and their tangible elements, I will use photo and video documentation, presenting each piece individually. Nevertheless, for the purpose of this research, the exhibition mockups have been outlined based on the proportion of that room. In the room, there will be a large screen along with an Oculus Rift headset and controllers for the VR experience, a podium and a movable light for the acrylic frames and the wooden shelf, a free-form frame made of sand around the maze model, and a short-throw projector to display the memory pieces on one of the walls. Once visitors step inside the room, they will face a fragmented collection of pieces scattered around; they will have the opportunity to immerse themselves in and test the VR experience, view the maze model, the acrylic frames, and the projection of Gro's memories on the wall. There will be a wall with additional information about the overall theme, several signage to narrate the pieces, and a display to present the VR equipment instructions (Figure 127-130).

| 127 |



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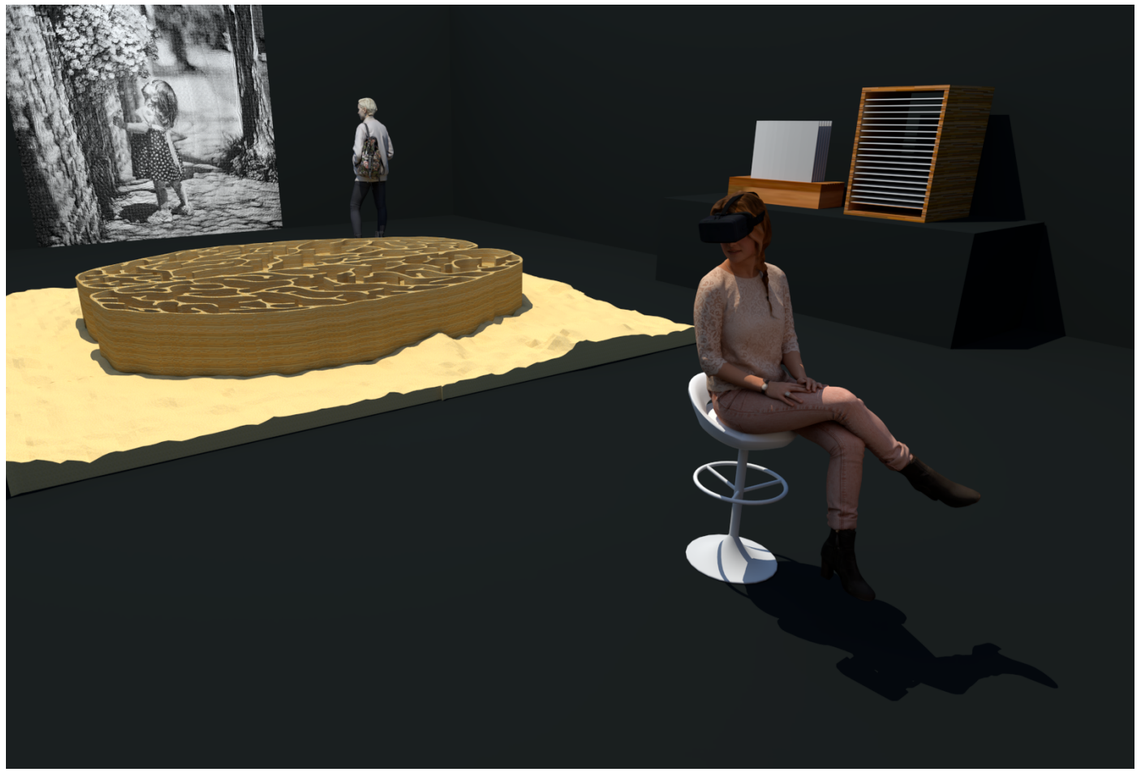

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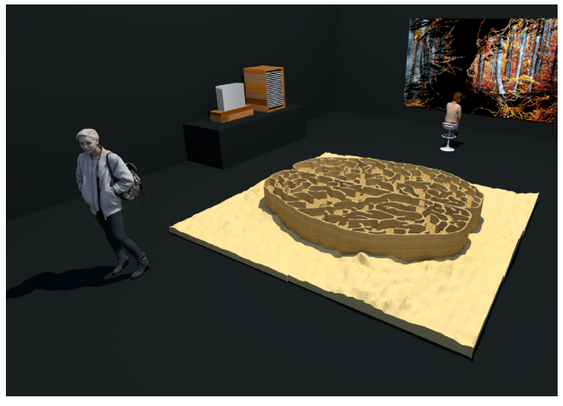

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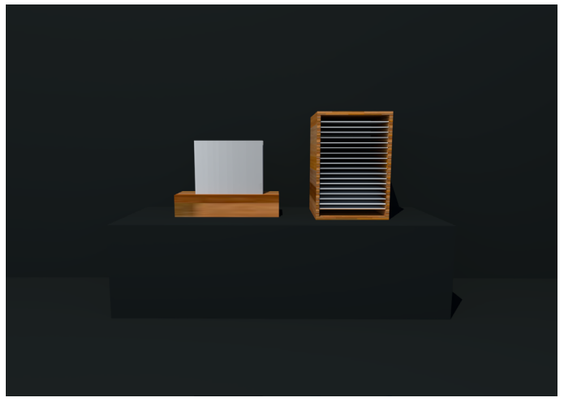

5. Discussion

In the following chapter I will address how the project's visual methods, outcome, and final concept relate to the main research question as well as the theoretical framework that I have outlined in the context chapter. I will also discuss how this project as a whole has benefited from multilayered design strategies. And to conclude, I will explain the project's limitations, potential development, and opportunities for real-world application, and point out opportunities for further artistic research.

5.1. Awareness and understanding of dementia

Low levels of understanding about dementia lead to numerous misconceptions about the disease and result in a stigma perpetuation which is, sadly, prevalent in most countries. Misperception happens on several levels: the wider population, people with dementia and their families, and healthcare providers. Many people are unaware of the range of symptoms associated with dementia. They are most likely to view memory loss as a sign of dementia, rather than other symptoms such as loss of interest or behavioral changes. When people with symptoms, or their relatives, believe that memory loss is a normal part of aging, they do not seek medical advice. The health profession has a role to play in this field by actively identifying symptoms in elderly patients and by providing information to at-risk patients. This is crucial for raising awareness, both among the general public and also the healthcare professionals.

At the heart of awareness-raising and understanding is the message that dementia is a disease that causes disability and is not an inevitable part of aging. Awareness-raising and compassion are essential for countering the fatalism and stigma that is often associated with dementia. They may also improve the ability of caregivers to better cope with looking after people with dementia.

A great example of this was The United Kingdom campaign *"I have dementia, I also have a life"* which showed a targeted approach in overcoming fears of a particular group within society. The campaign, which used television, radio, the press, and the internet to attract a 40–60-year-old predominantly female audience, featured people with dementia. As a result of qualitative research, the advertising, which aimed to raise levels of understanding was developed. While in previous studies, people who have dementia and their families expressed they felt stigmatized, the findings of the qualitative research, which was conducted with people who had little to no knowledge of dementia, revealed that what was being perceived as stigma was something very different. It demonstrated great fear of dementia, fear of getting diagnosed with dementia and fear of dealing with people who have dementia. Hence, the campaign was aimed at "normalizing" dementia rather than "medicalizing" it since the latter could lead to increased fear (National Health Service in England, 2017).

Additionally, numerous media outlets such as film, television, the internet, and social media offer opportunities for disseminating positive outlooks and messages about dementia. For instance, the documentary film, *"I Remember Better When I Paint"*, sends a powerful message about the abilities that can remain despite the diagnosis (Ellena & Huebner, 2009). While in this research study and practice, I shared a similar message as these cases do. I tried to take it a few steps further to cultivate emotional, and cognitive empathy.

5.2. To cultivate empathy

Empathy is the capacity to identify with or comprehend another's situation or feelings. *"To be with another in this way means that for the time being, you lay aside the views and values you hold for yourself in order to enter another's world without prejudice."* explained psychologist Carl Rogers. Empathy serves to give us insight and patience, leading to a better attitude for both people who have dementia and their caregiver or loved one. When we are empathetic, we genuinely try to understand and feel what someone else is going through. Furthermore, from an evolutionary point of view, it makes sense that human brains are built to feel with other people. *"We're a social species and would have never survived without each other"* describes Maia Szalavitz, author of *'Born for Love: Why Empathy Is Essential — and Endangered'*. Practicing empathy is harder than it seems though. Obviously, it is a lot easier to offer a tissue than an ear, particularly when it comes to the

people we disagree with, but *"feeling with"* others fosters growth and connection both individually and across society. Our empathetic ability solidifies as our brain develops. Not only do we become capable of emotional empathy (vicariously experiencing another person's feelings) but also cognitive empathy (placing ourselves in the mind of another). Cognitive empathy demands a more sophisticated capacity for language and a broader understanding that the world does not revolve solely around us.

Sharing in others' emotional experiences enables us to cultivate meaningful, supportive relationships. And if we regularly give support to others when they are struggling, we are more likely to receive support in our own tough times. Nonetheless, we do not always choose the empathetic response, in part because it does not always feel good. Ultimately, sharing in another's emotional experience can mean letting in difficult emotions such as distress, sadness, grief, hurt, and fear. Moreover, empathy — particularly the cognitive kind — is not necessarily an automatic process. It is actually a choice. Before deciding to do anything, we subconsciously weigh the costs and benefits of attempting to understand another person. It is easy to think that people might avoid empathy because they just do not want to feel bad. But what if it is because empathy is taxing, and exhausting? Trying to get into someone else's head and feel what they are feeling is grueling work.

Whether or not we do the work is partially based on our own state of mind. In order to feel with others, not only must we feel safe and calm ourselves, but we also need to be aware of our biases. The human brain subconsciously differentiates between in-group and out-group, and we are more likely to empathize

inadvertently with people who look like us. This bias also applies to people who think like us. Therefore, it is essential to find ways to bridge these gulfs and try to understand people with viewpoints different from our own. This should be extended to people who have dementia as well. The disease alters their perception of the world, but never takes away their humanity.

Where our culture tends to just focus on the disease, decline and loss, *'Persona'* attempts to reveal personality and remaining strengths of people who have dementia by highlighting the similarities and the feelings that are universally shared among all of us. This positive outlook challenges the stigmas that are often associated with dementia, and instead takes a humanizing act. Everyone is driven by universal needs, and if we can see beyond others' words and behaviors to understand their needs, we can empathize with them, because we likely have a similar need.

5.3. Embodied experience

In the real world, immersive technologies have unearthed a power to solve key communication gaps. The premise of the immersive technology is quite simple. Virtual reality is a fully enclosed digital environment that replaces the user's real world. Augmented reality is a digital overlay into the user's real-world environment. Mixed reality is a combination hybrid of both AR and VR or physical and digital. While pictures are worth a thousand words, immersive mediums like VR and AR can be worth a thousand pictures and videos and that exponential power is why immersive experiences are so boundlessly exciting. Among these mediums, the realistic, multi-sensory and immersive experience of VR provides an embodied perspective-taking opportunity that allows the user to live vicariously and visually through someone else's personal experience. It breaks down social boundaries and it connects us together better.

Traditional 2D photos and videos are staples for visual communication that will never be replaced. They often only offer a limited, sheltered glimpse of a full experience, but what if we could see beyond that? What if we could experience it first-hand too? Virtual reality brings an opportunity to bridge that communication by providing the brain with raw material from a real experience for a more whole and accurate simulation. Being able to show someone a past experience or take them to a distant place is so much more powerful than just telling them about it, and it is such a great learning tool because we learn through direct experience. We cannot provide our brains with the raw material from real experiences and boost human cognition, but we can hit the emotions at heart so one can remember them longer. That indicates the power of these technologies as

we are transcending communication difficulties. *"VR can accelerate new insights and help usher change, not through force or coercion but through the power of perspective."* Says Thong Nguyen, CEO at Roomera. In this research study, I explored a few ways to apply this sensory feeling to healthcare education and training framework using VR.

Simulation has a long history in medical and nursing education and is broadly used to train novice and expert educators for clinical skills, competences, and attitudes (Haugland & Reime, 2018; Grant et al., 2016; Aggarwal et al., 2010). Simulative experiences can be classified from low to high fidelity simulation based on their complexity and capability to display reality. This fidelity simulation spectrum includes applications such as task trainer, role-playing, gaming, virtual reality, computer-assisted training, standardized patient, and human-patient simulator with respect to their degree of computation (Francis, 2018). Dementia simulation is a recent development in the simulation field and there are emerging examples of its use in the context of healthcare training (Adefila et al., 2016) and within public awareness campaigns (Alzheimer's Research UK, 2016). Dementia simulations are also commercially available (Beville, 2002) and draw media coverage (BBC, 2017). The possibility of repeating complex learning situations and monitoring training by virtual reality simulation may enable productive learning (Ericsson et al., 1993). This raises the question of whether virtual reality might be an effective learning strategy to simulate interaction with people who have dementia to improve caring proficiencies. One approach consists of imitating encounters with people who have dementia in a virtual reality simulation to develop communication

skills or to reduce caregivers' anxiety (Hansen, 2008). Moreover, the potential of virtual reality intervention may consist of conveying the experience of living with dementia as examined by (Adefila et al., 2016; Wijma et al., 2018). Training of caregivers in a virtual setting could enhance sensitization and might be an effective way of preparing them for their encounters with people affected by dementia. Through this research study, some of these new methods of exploration that analyze problems and experiences have been assessed and developed as a chance for educational purposes of a virtual reality application.

There is only a limited body of research currently exists on the impacts of VR dementia simulation, but the available evidence is encouraging. A controlled trial performed in Australia showed significantly improved attitudes towards people who have dementia, in pharmacy and medicine undergraduate students, following a VR dementia simulation (Gilmartin-Thomas et al., 2018). A Dutch study showed that delivering VR experiences to family caregivers was feasible, acceptable, and led to substantial improvements in empathy, trust in own caring abilities, resilience, and positive interactions in the relationship with the person who has dementia. Moreover, a research study of health and social care apprentices indicated that exposure to a VR dementia simulation resulted in significantly improved empathy and compassion for people who have dementia (Adefila et al., 2016). Recently, several VR interventions have been developed to experience dementia. Alzheimer's Australia Vic has developed a VR tool that simulates the thoughts, fears, and challenges of a person living with dementia on a wide screen.

Alzheimer's Research UK also launched a VR smartphone app - *A Walk Through Dementia* - intended to give the public a glimpse of what it is like to live with dementia (Alzheimer's Research UK, 2016). The Dutch Into Dementia, a simulation cabin in which visitors experience typical daily scenarios of a person who has dementia, has been created for informal caregivers and healthcare professionals (Hattink et al., 2015). A pilot research study reported that Into Dementia was beneficial, helped to provide better treatment, and understanding of people with dementia (Hattink et al., 2015). And finally, the Alzheimer Experience, an online interactive intervention, was designed in the Netherlands with the same purpose and target group (Prins et al., 2020).

Compared to the previous examples, *'Persona' VR experience* adopts an inclusive approach that stimulates diverse emotions, invites the users' imagination, and includes a multilayered sensory experience covering the most common types of dementia including Alzheimer's disease, vascular dementia, and Lewy body dementia. It gives a tangible way to begin to understand the discrepancies between what we think, what we feel, and what we believe we already know about dementia. Through this application, regardless of your physical location, whether you are at home or anywhere else, you can use a VR headset and virtually experience a tour into the mind of an individual who has dementia in just a span of several minutes, as if you are really there. Not only is this a visual, educational, and accessible tool for caregivers, it is also an experience for those who are willing to embrace the fragility of the human mind.

6. Conclusion and opportunities

6.1. Limitations, areas of improvement

The project has been focused on sparkling awareness within the healthcare community, among informal caregivers and the public to enable the first steps towards an inclusive culture. But because we know that cultural change takes time, and hopefully the project will help inspire caregivers to continue this process, I was also being restricted by the time frames of the master program and the Covid-19 pandemic. Some areas of the project could have been developed further on; involving more people that have first-hand experience with either the design methods used in the project or the caregiving issues.

Despite the fact that I had the opportunity to discuss briefly the principles and some of the cultural prompts with healthcare specialists and formal caregivers, I would have liked to involve them more in collaborative sessions. Even maybe, develop joint sessions between the healthcare team and informal caregivers like families or friends of people who have dementia and by reaching out to the larger audience in public. In order to continue working with awareness at a more macro level, it would have been important to develop similar sessions with other healthcare specialists that are familiar with dementia. This could have been a good opportunity to test the cultural prompts to continue developing them as well. Placing the intentions of the project in a more concrete context.

With regard to the practical process and overall outcome of *'Persona'*, the project had many successes and shortcomings. Each area of research presented unique challenges, which required analysis, experimentation, creative problem solving, and interdisciplinary collaboration. Through a combination of several design methods, *'Persona'* sought to transform big concepts into realized solutions. Knowledge gained throughout the study period significantly influenced one another, and the project was able to drive itself further along the way.

Even though the evolution of *'Persona'* became an organic chain of events, future iterations of the project may benefit from a different set of explorations. In hindsight, the VR experience and the memory pieces may have benefited each other if they had both begun at the same time. If testing of the visual narrative and content had begun earlier in the process, any technical issues or aesthetic choices could have been revised far before the end of the study period and the final output. Moreover, if the situation with the Covid-19 pandemic was resolved and the restrictions on visiting nursing homes were loosened, the accuracy for selecting the content that matches both pieces would have been improved by implementing the healthcare specialists' feedback.

In the future, an active testing cycle of the VR experience would be valuable to the project. It is worth noting that the project was created from a designer's perspective, so there was some room for uncertainties, such as coding and software knowledge for VR development and visual content creation. To fill in those gaps, future collaboration with designers and experts may provide valuable information to further validate the project's findings.

6.2. Real-world application, potential artistic research

Caregiver's distress due to the overwhelming, altering nature of dementia is a bigger-than-self issue that cannot simply be solved by smart design solutions. Conversely, design can assist and be a part of a broader change by raising awareness, and, in contrast to its usual practice, question and challenge our perception of the world. Instead of extending the status quo that often medicalize or stigmatize the disease, our practice should mobilize inclusive knowledge that unites us all. By unveiling some of the hidden layers of the disease, and highlighting the human aspects of dementia through multiple storytelling techniques, *'Persona'* provides an example of how design can communicate a humanized overview of dementia.

Focusing on educational approaches to improve caregivers' knowledge about dementia is simply meant to exemplify the problem in one area. There are, however, many other facets of the disease and caregiving problems, like social interactions, anxiety, and subjective wellbeing that are and will be affected. The first instalment of my project has the limited scope of the graduate exhibition at KMD and an online exhibition platform. I am aware of these limitations, but am using the exhibition, and this thesis, to gather further interest from the healthcare community, design and the scientific fields, so that I might be able to expand the project's reach in the future. In order to initiate effective changes, the critical realm of design needs to find ways to reach and appeal to the broader public and not just the culturally interested groups.

In an attempt to find a way to release that friction from exhibition halls and showrooms and rather push the project's reach beyond the boundaries of the school, the VR experience has been packaged so it can be remotely distributed among the users, regardless of their location. This highlights a potential of the VR experience and its flexibility. However, to properly prepare the components of such an experience for a public package, a thorough framework and many more tests are required. Furthermore, the VR experience may be utilized as an initial learning step towards improving the in(formal) caregivers' understanding of the disease, and its varied nature in the educational programs of nursing homes or health-related seminars and research studies.

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