(un)conditional

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“A thousand times

we die in one life.

We crumble,

break and tear apart

until the layers of illusion are burned away and all

that is left, is the truth of who and what

we really are.”-Teal Scott

Thank you

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Whenever I think of my grandma, my mind begins to recall the smell of fresh warm baked goods in the kitchen, apple dumplings, orange white chocolate chip cookies, her laughter and eyes lighting up after telling a quirky joke, frozen blueberries stocked high in the freezer for anyone to munch on, countless stories she would share about the past, and most of all her love. My grandma was so full of life and love that you could taste it in her food and feel it in her presence. I remember my mom saying, “That’s how grandma shows her love, through her food and through her stories.” However, she does not cook anymore, and her stories are not quite the same. She is still present, she still talks and asks questions, but the conversation has changed.

Firstly noticeable, her speech declined and then her memory—some of the main symptoms of Alzheimer’s disease. When trying to share a story she would get stuck on words, sometimes stammering and repeating them, sometimes mixing up words that have similar beginning letters, but never stopping the conversation to correct herself. I feel like she did not want to bear witness to what she was struggling through, except we were all aware.

Over time her presence switched back and forth through what seemed like consciousness and awareness to a blank daze in her eyes. I could feel her struggle with what was happening within as parts of her seemed to be slipping away. I remember being behind her in line for food as she was trying to scoop out pasta onto her plate. Her hand seemed limp and it seemed as if she forgot how to use the spoon. I lovingly slipped the spoon from out of her hand and said “Oh grandma, here like this” as I put food onto her plate. I was unsure how I felt about that, feeling slightly embarrassed and wondering how she felt and where her mind was.

As more time has passed, I have seen the struggle for control diminish from her eyes. To me she has progressed into a stage of content. My grandpa and her still live in their house along the Chesapeake Bay. He now fills the role of caretaker of her and the house, which she once did.

We have seen how the process has taken a toll on him too. He barely eats and has lost a great amount of weight. He still stands by my grandma in every way possible and tries to find ways to slow down the progression of the disease, while refusing to let someone else in to take his role.

My last visit to my grandparent's house, I spent my time inside with my grandma to keep her company. I have always loved visiting them, except now I find myself holding back tears when I see her. To put my arms around her body and hug the person who had always been there for me, yet does not know exactly who I am anymore, is heartbreaking. While growing up, I feel as if my grandma saw me. She gave me the support and understanding that I needed, and I always felt like I had a voice when I was with her. Now as she goes through her struggle, I want to give her a voice and understanding like she gave me.

Through it all, my grandma seems to still be full of life. She still brings up parts of the past, but with major pieces of context missing, asks questions about what we are all talking about, repeats certain things over and over, tells us that she loves us and to always come back to visit without personally referring to us, and even still makes witty jokes. While both of us were on the front deck, she was talking about her new neighbors and how they were so unfriendly. She exclaimed that, "I always say hi, how are you? But they never respond!" It really seemed to bother her, so much that she told me she wanted to keep saying "hi, how are you?" to them and when they would finally respond with "why do you keep asking that" she would reply with "I don't know what you're talking about. I can't even write my own name." Even though so much has changed, it shows to me that she still has part of herself and is aware of her condition. The same day, I was cleaning the windows inside, and I heard her come up behind me and say, "Oh honey, you don't need to do that!" And I froze. And immediately replied with, "It is okay grandma, I don't mind" as I continued to clean and gaze out the windows, afraid to interrupt

what seemed like a moment of clarity. There was a change in her voice that made everything feel normal again. That moment unveiled to me that the effects of Alzheimer's on the mind as well as human nature is a mystery. What happens to one's mind when going through the disease, how is memory affected and more importantly what happens to one's self and if there even still is a conception of self, and how do we all respond to this change? All of these questions circulate my mind, but I am unsure if they can all have a definite answer. All I know is that Alzheimer's is my biggest fear.

(Un)conditional is my outlet in exploring the effects of Alzheimer's disease on the mind and one's life. Through three crafted busts—one clay, one wax, and one paper—I want to convey the internal effects of Alzheimer's on the exterior of the busts for the viewer to visually see. To me, each material is malleable and mirrors life and perception of self that can be continuously shaped and formed, but also each is delicate and vulnerable to outside forces in their own way. The three materials also serve as a representation of time and regression, clay being the strongest to paper being the most delicate. As Alzheimer's progresses, so does the weakening of one's mind. The three busts rest on a large pedestal and by each one is a pair of headphones that play an unedited recording of one's fluid memory. Each bust will play the same recording, but each will be set at different intervals so that the viewer may enter the memory at different points in time. Without Alzheimer's, one does not know the effects on the mind. Therefore, I want to create an artist's perception of the mind and how memory and identity fall vulnerable to Alzheimer's, and what it may feel like to be going through it.

Alzheimer's is a disease that affects roughly 5 million Americans, and is currently ranked as the sixth leading cause of death in the United States (NIHSeniorHealth 1).

It is a form of dementia that mainly causes problems with memory. However, over times this progressive disease can cause difficulty remembering newly learned information, carrying on conversations, responding to one's environment and performing daily tasks and speaking, as well as impacting one's cognitive ability and behavior (Alzheimer's Association 1-2). But how does all of this happen? The Alzheimer's Association explains that:

> The brain has 100 billion nerve cells (neurons). Each nerve cell connects with many others to form communication networks[,and each group] of nerve cells [has] special jobs. Some are involved in thinking, learning, and remembering, [while o]thers help us see, hear and smell (3).

The Alzheimer Association informs that "scientists believe that Alzheimer's disease prevents [cells from fully operating. And that] as damage spreads, cells lose their ability to do their jobs and eventually die, causing irreversible changes in the brain" (3). The NIH Senior Health's article on Alzheimer's disease explains this information more in depth and what harmful changes are taking place in the brain. They illustrate that:

> The damage at first appears to take place in cells of the hippocampus, the part of the brain essential in forming memories. Abnormal protein deposits form plaques and tangles in the brain[,and o]nce-healthy nerve cells stop functioning, lose connection with each other, and die. As more nerve cells die, other parts of the brain begin to shrink. By the final stage of Alzheimer's, damage is widespread, and the brain tissue has shrunk significantly (2).

Alzheimer's does not discriminate towards age, race or gender. It can strip one of his/her past and cut them from a sense of their future. It takes a toll not only on those with it, but those close to them as well. Because a person's ability decreases while the disease progresses, he/she becomes dependent upon family or a caregiver almost in the way of a child. Nicci Gerrard, author of the article "Words Fail Us: Dementia and the Arts," beautifully describes that:

> The child learns to shape sounds into words and makes boundaries around things; they tell stories and impose a narrative pattern on chaos-only in this way can the flooding world be comprehensible and endurable. But the dementia person unshapes, undoes, disintegrates, unravels-from the formation of the self and language to its drastic unmaking. Words become mere sound again (5).

Through my chosen imagery, I want to convey the progressive regression of one's self with Alzheimer's and its ability to unshapen and disintegrate one's self.

The sense of one's self is created by his/her experiences and memory. Luke Mastin, author of the article "Human Memory" believes that memory "is an important part of what makes us truly human, and yet it is on the most elusive and misunderstood of human attributes (1). The act of storing memory is ambiguous. It is held within multiple components of the brain. Mastin conveys that:

> Each element of a memory (sights, sounds, words, emotions) is encoded in the same part of the brain that originally created that fragment (visual cortex, motor cortex, language area, etc.) and recall of memory effectively reactivates the neural patterns generated during the original encoding. Thus a better image might be that of a complex web, in which the threads symbolize the various elements of memory, that join at nodes or intersection points to form a whole rounded memory of a person, object or event. This kind of distributed memory ensures that even if part of the brain is damaged, some parts of an experience may still remain (1).

For instance, whenever my family and I visit my grandparents, my grandma constantly brings over old pictures and asks us if we know who is in them. However, they are always the same ones—a picture of her in nursing school and my grandpa's graduation photo. She loves to show them to us and reveal that they are of her and my grandpa. But my grandma never seems to bring over any recent photos of my aunts, uncles, cousins, or of me; even though, they are hung along the walls of their house. I guess in the end, we do not get to choose what or who we remember.

Also within memory, there is short-term and long-term. Richard F. Thompson and Stephen A. Madigan, in their book *Memory,* define short term memory or immediate memory as the "retention and retrieval of very recently presented information such as new telephone number [that one] just looked up" (11-12). They also inform that short-term memory involves that idea of working memory as well, which includes "retaining new information but also involves the transformation and use of that information, retrieval of knowledge for long-term memory to integrate with the new information, and awareness of your surroundings" (Thompson and Madigan 12). Thompson and Madigan then describe long-term memory as "the vast store of information [one] possesses and [is] not aware of unless [he/she] calls it up" (24). The vast store of information that one possess includes one's knowledge of facts, language, and vocabulary, as well as all the skills learned such as walking, talking, playing an instrument, and even emotions felt that can be applied to ongoing experiences and understandings of the world (Thompson and Madigan 1).

Even long-term and short-term memory are part of broader aspects of memory called explicit (declarative) and implicit (non-declarative). Larry Squire, of the University of California, San Diego explains the distinction of explicit memory as "what most people mean by memory. […The term signifies] the ability of individuals to consciously and deliberately access and describe the contents of their memory" (Thompson and Madigan 8). Thompson and Madigan then explain implicit memory as "memory without awareness and that it involves several different kinds of memories. But even if we are not aware of [them,] they are still very important. Explicit memory seems to involve a conscious recollection of past events and knowledge and implicit memory involves an unconscious recollection of skills that one knows how to do such as the act of riding a bike. One does not have to think about it in order to be able to do it. Thompson

and Madigan also convey in their book that "one of the main reasons that memory theorists originally postulated the existence of these two different systems was the fact that certain kind of brain damage seemed to impair explicit-declarative memory but not implicit procedural memory" (13). There is reason to believe that this applies to brain damage from Alzheimer's as well. Alzheimer's is found to have major effects on the brain in areas that involve the storage of memory and learning such as the hippocampus. It is possible that as Alzheimer's disease progresses it has a larger effect on one's ability to use explicit memory rather than implicit memory. For example, my grandma was always tiding up and cleaning her house. Now that she has Alzheimer's, she is still able to walk on her own, and you will still find her tiding up and putting things away, but without knowing what she is doing. Her mind still has the urge to perform that task, but the mail that was once on the kitchen table might end up at the bottom of the bedroom closet and one's cellphone who knows where. However, Thompson and Madigan believe that without memory, there can be no mind.

Alzheimer's disease challenges notions of self and what happens when memory declines. Stigma surrounding the disease insinuates that a person with it is no longer his/herself. Alzheimer's has the ability to make one feel as if they have lost the person he/she loved, even though that person is still alive. In her article "Alzheimer's Challenges Notions of Memory and Identity," Tania Lombrozo claims that "the disease [seems] to threaten the persons "true" or original self. As memory [declines so does] the individual's identity. […] This perception rests on two assumptions: one about the way we track people's identities over time and the other about the way Alzheimer's affects the human mind" (2). In Elizabeth Herskovits article "Struggling over Subjectivity: Debates about the "Self" and Alzheimer's Disease, she addresses that "the diagnosis of Alzheimer's is a much-feared stigmatizing label that carries with it the force of a

sentence of social death"(152). And with this stigmatizing label comes a sense of dehumanization or debasement of self (Herskovits 152). Those with the disease are characterized by others as the living dead that exist within their own private hell of devastation and destruction, merely shells of their former selves. However, Herskovits adds that "although the dominant representation of personhood in [Alzheimer's disease] is bleak, there have been, especially since the mid-1980s, dissenting voices that have endeavored to restore dignity and resuscitate the humanity of individuals diagnosed with Alzheimer's" (154). In her article, Herskovits applies sociologist Jabrium F. Gubrium's reasoning. Describing those with Alzheimer's, he believes that their "humanity is still there [and that they still have] feelings. What the disease destroys is the ability to appropriately express them" (Herskovits 154). Gubrium observed many caregiver support groups for Alzheimer's patients and within some of their newsletters they wrote that:

> under the veil of the disease is a real person. While science and medicine can perhaps measure the patient's responses to what is going on around him at the present time, no one can know what the patient is actually thinking or feeling.[…W]e can hate and resent the disease—we can still love the person (Herskovits 154).

Another newsletter expressed that "no one has the direct access to the feelings of those concerned, only [to] their expressions [and] outward signs" (Herskovits 154). Those with Alzheimer's may then still maintain a mind and have feelings but lack the ability to fully express themselves properly, resulting in misunderstandings and confusion from others. Herskovits notes that "what appears to be at stake in these competing voices [surrounding the debate about self in Alzheimer's] is our very notion of what comprises the self and what constitutes subjective experience" (146).

Herskovits also applies the work of Steven R. Sabat and Rom Harre in defining the notion of self. They define two selves. One self is defined as "personal identity or continuity of one's point of view, which persists to the end" (Herskovits 156). The other self is defined as "multiple public personae, that is, as an intersubjective public project that can be lost or debased by stigma rather than by the disease itself" (Herskovits 156). Sabat and Harre address that:

> the primary cause of the loss of self is the ways in which others view and treat the Alzheimer's sufferer. For example, just because the listener is confused does not mean the speaker is confused.[I]t is only the attribution of confusion that threatens the personhood of the individual diagnosed with Alzheimer's" (Herskovits 156).

Therefore, language becomes a barrier to understanding. Tom Kitwood, a psychologist and pioneer in the field of dementia care proposed a model of the "dementia process that pivots on dialectical interplay between neurological and social psychological factors" (Herskovits 156). Kitwood believes that:

> based on the fact that human beings are far more deeply affected by [the] social psychology that surround them than is commonly recognized, aspects of malignant social psychology (such as disempowerment, infantilization, labeling, banishment, and stigmatization, among others) deprive the already neurologically impaired individual of his or her personhood, resulting in further neurologic damage" (Herskovits 156).

Robert Bogdan and Steven J. Taylor identify four ways in which the disabled person's humanness status is maintained by others (Herskovits 156). They are outlined as attributing thinking to the other, seeing individuality in the other, viewing the other as reciprocating, and defining a social place for the other" (Herskovits 156). Bogdan and Taylor believe that "the self is an intersubjective project in which what and who others, as well as we, are depends upon our relationships with them and what we choose to make of us" (Herskovits 156). Another suggestion towards Alzheimer's and the restoration of humanity of the person diagnosed with the disease is that "Alzheimer's [could be] a mode or mechanism for becoming more healthily and

authentically human" (Herskovits 156). In their prescription for dementia care, psychologists Tom Kitwood and Kathleen Bredin locate the problem outside of the person with Alzheimer's. They believe that "the problem of dementia arises from a damaged, derailed and deficient intersubjectivity" (Herskovits 156-157). Kitwood and Bredin state that:

> it is arguable that the general pattern of everyday life, with its hypocrisy, competitiveness and pursuit of crass material is, from a human standpoint, deeply pathological, while the neurologically impaired elderly are more authentic and honest, healthier in their straightforward (inter)dependence on others and in their propensity to live in the present (Herskovits 157).

I find truth in this statement and the feeling that perhaps Alzheimer's is a way for one to find his/her true self and moral.

Within philosophy, many people have argued that our personal identity is rooted in our accumulated and continuous memories (Lombrozo 3). However, a collaboration between psychologist Nina Strohminger and philosopher Shaun Nichols claim that our identities come from our moral character than from our memory and intellect (Lombrozo 3). An article by Alison Gopnik, "Is our Identity in Intellect, Memory, or Moral Character" explains Strohminger and Nichol's claims and the study that they performed in order to conclude this reasoning. Within the study, they compared different types of neurodegenerative diseases in a 248 participant study. The diseases compared were fronto-temporal dementia (FTD), amyotrophic later sclerosis (ALS), and Alzheimer's disease. FTD is considered the second most common type of dementia, which rather than attacking parts of the brain that deal with memory, it damages areas of the brain that are involved with impulse control, behavior, and emotion. As a result, people with FTD may become subject to changes in personality and impulses that may result in lying or stealing, even though they may retain memory and intellect. ALS is a disease that affects one's ability to control his/her motor skills. Throughout the study, researchers asked family members

or other caregivers of people with these diseases to fill out a questionnaire. The questionnaire involved questions regarding how the patients changed such as with memory, cognitive ability, and moral behavior. At the end of the study, researchers found that those who cared for people with FTD felt that they had become different people more than the caregivers of those with Alzheimer's or ALS. Results showed that within all three groups, changes in moral behavior predicted changes in perceived identity rather than those of memory and intellect (Gopnik 2-3). Gopnik alludes that "these results suggest something profound. Our moral character, after all is what links us to other people. It is part of us that goes beyond our own tangle of neurons to touch the brains and lives of others" (3).

Although what happens within the mind of another person is always a mystery, perceiving other's minds is an important component of social life. In Adam Waytz, Kurt Gray, Nicholas Eply, and Daniel M. Wenger's article, "Causes and Consequences of Mind Perception" they convey that:

> Other minds not only create a sense of understanding, they also create a sense of social connection with another entity. Considering another person's mental states by explicitly adopting his or her perspective increases the perceived similarity between the self and the other person (2).

I believe that as human beings we search for connection and understanding within our lives. How one is perceived by others may have an effect on one's identity to others as well as a sense of personal self. Waytz et al. claims a "serious ethical problem in everyday life, however, is likely to come from seeing too little mind in others" (386). This suggests that if someone perceives another person as different from his/herself, than the other person will seem more mindless. Therefore, it is important to go beyond one's own self in order to be able to perceive and give understanding to others. In regards to Alzheimer's it is important for family and caregivers to try

and give those with the disease understanding and to push past the notion that they no longer have a mind. For example, whenever my family and I communicate with my grandma, we treat her as we always did and go along with anything she has to offer. For instance, during a visit, she always asks the same questions such as what I am studying in college, and each time I give the same honest response.

Hazel Macrae, author of the article "Managing Identity While Living with Alzheimer's Disease," supports the idea that "holding onto former selves is especially difficult when others impose an illness identity on the person (1). One's environment and mindset with disease can determine the effects and progression of Alzheimer's on feelings of self. Throughout her article, MacRae discusses her study on the impact of the illness on identity, and concludes that her results indicate that "given the necessary resources, persons with Alzheimer's can live meaningful, purposeful lives and creatively manage to protect and preserve identity" (1). Within her article, she includes a number of points of view from other studies that challenge the assumption that loss of self is an inevitable outcome of Alzheimer's. One of the perspectives is of S.R. Sabat and M. Collins (1999) whose study conveys that "individuals still possess an intact sense of personal identity and have the ability to construct social identities when they obtain the necessary cooperation of others" (MacRae 294). This claim perpetuates the idea that if others perceive those who are different such as with Alzheimer's disease as mindless, than the individuals with the disease may not feel understood and may undermine identity. MacRae's study entails face-to-face interviews with nine individuals all diagnosed with early stages of Alzheimer's (MacRae 295). Through a series of open-ended questions on topics that included "reaction to the diagnosis: the impact of Alzheimer's on their daily lives, relationships, and interactions; their outlook on the future; their perception of other's view and treatment of them;

and their current view of self and extent to which they believed they had changed as a result of their illness" (MacRae 295). Her study found that if one took a positive approach to being diagnosed with Alzheimer's, then he/she considered him/herself to still maintain the same feeling of self; even though, he/she may experience difficulties with memory. A participant from another closely related study beautifully revealed his feelings that "I'm still the same person I've always been, it's just that now I'm me with Alzheimer's" (MacRae 297). MacRae's participants maintained a sense of self through acts of normalizing—adopting a mindset that makes the best of a situation (possibly with humor) and continues daily routines in life that focus on what he/she is able to do; living in the present—living day-to-day and in the immediate future; altering aspirations and reappraising priorities—adopting strategies that allow one to continue things that he/she enjoys or that are similar; social comparison—a way of evaluating self and constructing identity through the mindset of "things could be worse' or rationalizing that others are going through the same thing; life review—reflecting on one's life and previous accomplishments in order to adapt to significant changes in his/her life; and by constructing self—constructing new dimensions of self by possibly getting involved in helping others which can enhance one's self by making him/her feel useful (MacRae 298-301). Fortunately in this study, Alzheimer's participants had a positive environment consisting of family and friends that enabled them to live active lives and manage a sense of self. A common theme mentioned by all participants in MacRae's study was to stay socially engaged and active as well as a sense of independence that makes him/her feel useful. In regards to my grandma and my family's perception of her and herself, we feel like she is very much still her. Even though there has been a lot of change and loss in her memories of who we all are, she is still very talkative, vocal in how much she loves us and wants all of us to visit. She still even expresses to my grandpa that she needs to be able to do

things and needs to be felt needed. In the end, MacRae's study reveals the need for a supportive environment for those who have Alzheimer's, even though understanding of how the disease will progress is left to be found.

It is with no doubt that exploring the experience and mind of those with Alzheimer's and dementia can bring about a powerful way of thinking throughout time, place, and identity. Writer in the British newspaper, the *Guardian*, Christopher Ecclestone wrote about his father with Alzheimer's explaining that "rather than trying to pull people with dementia into your world, you have to enter theirs" (Gopnik 3). The arts is a valid outlet that allows others to try and enter that world.

In addition to MacRae's study on managing identity while living with Alzheimer's, Anne Davis Basting, author of "God is a Talking Horse: Dementia and the Performance of Self" perpetuates the importance of giving those with dementia a voice as well as living in the present moment. In her creative project, *Time Slips*, Basting facilitates storytelling workshops that give the role of story teller to those with Alzheimer's. Common themes with the stories told are of "longing for freedom, acceptance, and intimacy with family or lovers (Basting 84). She explains that "at the root of the project was an effort to encourage creative expression among people with Alzheimer's in a form that could capture the complexity of their worlds and our relationships to them (Basting 79). The project allowed those with the disease to interact with others in a way that did not rely on memory and that gave them a meaningful role to play. Basting conveys that the *Time Slips* project was about creating the clear distinction of focusing on who those with Alzheimer's are now rather than focusing on who they were (80). She described that "by releasing the pressure to remember their pasts, the creative storytelling workshops invited any and all forms of communication and allowed participants to hone what communication skills

they retained" even if they were just repeated sounds (Basting 79). The stories in their raw form are what Basting was hoping to capture. She felt that as "the answers accumulated, the storytellers ushered us away from the logic of the outside world and into a realm between imagination and memory—ours and theirs" (82).

Through experiencing and researching my grandma's tribulation with Alzheimer's, I personally feel that those who have the disease still have a mind and sense of self. But then again, I am projecting my mind's perception. Alzheimer's is often surrounded by the stigma that because one's cognitive ability and memories are eroded they then no longer are his/herself. However, when one's memory is challenged, his/her morality is found to be left behind. And that through Strohminger and Nicholas research, morality is found to be the foundation for human connection and the defining factor of self. It is important for others to then give support and understanding to those with Alzheimer's in order for them to be able perpetuate a sense of self. People with this disease want to belong and feel accepted and understood just like anyone else, and it is difficult in a country that prides itself on individualism and independence. Ultimately, how someone else perceives you is how you are perceived.

Most of my recent work has been around the theme of identity in regards to self-discovery and reflection of one's self. Through the process of my work, I tend to find answers and understanding to my questions about life. As I work with my hands, my mind works in unison as each movement and mark made is a reflection of my thoughts and feelings. The themes in which I work with and my feelings about process are very similar to the artist Paige Wright. She beautifully revealed that:

> There is a place where we lose ourselves. Some people call it a happy place or spiritual experience or meditation. I find that place within the studio. Human beings need a balance between the physical and the mental. The studio is where there is no hierarchy between movement and thought;

> one has to think to move and move to think. Ceramics is a tool I use to investigate identity. Process becomes a metaphor for understanding. There is a filtration of information between what I look at and what is produced out of my hands. The marks and movements recorded in the clay become my thoughts (Wright).

By researching Alzheimer's and creating my project *(un)conditional*, I feel as if it became a process that allowed me to embrace my grandma's fate and to come to terms with the possibility of obtaining this outcome. As well as to listen more to some of the last written words she consciously left with me—"life is not measured by the number of breaths we take, but by the moments that take our breath away"—Maya Angelou. For to live every moment to the fullest and to embrace the present, for sometimes that is only what we have.

I dedicate my senior project to my loving grandma, Ruth Ann Anderson.

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