

11-15-2018

## Fading Away

Alyssa Roberts

*University of Hawai'i at Mānoa*

Follow this and additional works at: <https://kahualike.manoa.hawaii.edu/horizons>



Part of the [English Language and Literature Commons](#)

---

### Recommended Citation

Roberts, Alyssa (2018) "Fading Away," *Mānoa Horizons*: Vol. 3 : Iss. 1 , Article 18.

Available at: <https://kahualike.manoa.hawaii.edu/horizons/vol3/iss1/18>

This Creative Work is brought to you for free and open access by Kahualike. It has been accepted for inclusion in Mānoa Horizons by an authorized editor of Kahualike. For more information, please contact [sheila.yeh@hawaii.edu](mailto:sheila.yeh@hawaii.edu).

# Fading Away

ALYSSA ROBERTS

Honors 101 (Introduction to Research and Creative Work)

Mentor: Professor Susan M. Schultz

## Artist Statement

This memoir examines the numerous ways an illness can affect an individual and their loved ones. In addition to its physical effects, an illness can also take an immense, emotional toll on the individual and heavily alter their relationships with those around them. While some may become overwhelmed with their loved one's illness, family and friends who choose to adopt a caregiving role embark on an inspirational yet difficult journey themselves.

Witnessing my grandmother's battle with Alzheimer's disease enabled me to realize an entire new aspect of illnesses, and my goal for this memoir was to embody this aspect. Although this piece was written about my grandmother's Alzheimer's, its main message can be extended to anyone with any type of illness and anyone who has found themselves caregiving for another.

This memoir holds a special place in my heart as my grandmother is someone I have adored and admired ever since I was a child. I hope this piece will reveal several of the physical and emotional effects that an illness can have on an individual and, furthermore, provide ways for the individual's loved ones to manage caregiver's stress.

“Hi, everyone! Thank you so much for picking me up.”  
“No problem,” my parents replied.

My popo<sup>1</sup> wore her usual, gentle smile as she got into the car. Being busy with my freshman year of high school, I did not get a chance to see my grandmother for two or three months. However, the school year had just finished, and to celebrate, my parents decided that we should all go out to lunch.

We backed out of my popo's driveway and turned onto the main road. We had just reached a red light at the first intersection when my grandmother began rubbing her arms.

1 “Popo” (when used as a proper noun) or “popo” (when used as a common noun) is Chinese for “grandmother.”

“Aiyah. You cold, Alyssa? You need a blanket?”  
“No, I think I'm okay. Thank you, Popo.”

Her eyes lingered a few seconds longer, scanning my body up and down to ensure my warmth. She finally looked back up at my face, and I smiled to reassure her of my contentment. A few moments later, she turned to me again, rubbing her arms.

“Alyssa, you not cold? You need a blanket?”

“No, I'm okay.” I watched my grandmother's worried eyes and added, “Thank you, Popo.”

I reached down under my seat for my purse when I heard again, “Aiyah, it's so cold. You need a blanket, Alyssa?”



This piece was written while I was a freshman in the Fall 2017 semester and served as my final essay in Honors 101: Introduction to Research and Creative Work at Mānoa with Professor Susan M. Schultz. Although I am a Biology major, I have always been passionate about writing. This memoir allowed me to utilize my two interests to touch upon a significant subject in my life. As a member of the University of Hawai'i's Doctor of Medicine Early Acceptance Program, I plan on continuing my education after graduation at the John A. Burns School of Medicine. My hope is to earn a medical degree and spend the rest of my life practicing in Hawai'i, not only focusing on patient care but the health of the patient's family and caregivers as well.

*Mānoa Horizons*, Vol. 3, 2018, pp. 95–99  
Copyright © 2018 by the University of Hawai'i at Mānoa

I glanced at the stoplight and then at my mother, whose face narrowed with concern. The light was still red.

"I'm okay. Thanks, Popo."

• • • • •

I always considered my popo to be my second mother. As a child, I stayed at her house more than I stayed at my own. Every day, my popo vigilantly babysat me from the moment my mother dropped me off at six in the morning to the moment she picked me up at ten at night. When my parents went on business trips, I would stay at my popo's house for several weeks at a time. To say that my grandmother spoiled me is a complete understatement. Dressed in the baby pink pajamas that my popo sewed for me herself, I spent every night lying in her bed, nestled in a mound of all the blankets that she owned. My popo would climb upstairs to her bedroom and bring me my favorite blue sippy cup filled with warmed milk. We would then watch a marathon of *Animal Planet* shows about puppies until I slowly drifted to sleep. As I grew older, my popo continued to spoil and care for me in the same manner. Whenever she knew I was coming over, she would walk across the street to Times Supermarket, buy boxes of my favorite Häagen-Dazs vanilla ice cream, and have a huge bowl ready for me as soon as I walked through the door. Eventually, as I became busier with school, conversations with my popo became rare; I would only see her on holidays or at family gatherings. I noticed my popo's memory was worsening, but I always attributed this decline to her old age, not to an actual disease. When I discovered that my popo was diagnosed with Alzheimer's, I was overwhelmed with shock. I immediately thought back to the movies and television shows I had seen that featured characters with the disease. Some of those characters could not even remember their own family members. Sure, my grandmother would repeat herself and ask the same question a few times, but her memory was not nearly that bad. How could she have the disease?

• • • • •

Before my grandmother's diagnosis, I did not know much about Alzheimer's. My knowledge of the disease mainly came from what I had seen in the media. However, after my grandmother's diagnosis, I wanted to learn more about the disease and what it would mean for my grandmother's future health. I began by researching *what* exactly Alzheimer's disease is. I discovered that Alzheimer's is an irreversible, chronic brain disorder that greatly impairs one's cognitive and functional ability.<sup>2</sup> It is also a progressive disorder that "slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks" as one moves from the mild to moder-

2 James Soukup, *Alzheimer's Disease: A Guide to Diagnosis, Treatment, and Management* (Westport, CT: Greenwood Publishing Group, 1996), 11.

ate to severe stage.<sup>3</sup> In addition, Alzheimer's is the most common form of dementia, the general term for a "loss of cognitive functioning."<sup>4</sup> Sadly, despite its prevalence, there is currently no cure for Alzheimer's or any way to stop its progression, although several medications have been created to temporarily treat symptoms.<sup>5</sup>

I was frightened to learn that Alzheimer's is incurable. Because there is no cure, I wondered if there is a way to prevent the disease. I wanted to know more about *how* Alzheimer's develops. I found that most cases of Alzheimer's are said to be a result of uncontrollable factors such as old age and family history.<sup>6</sup> Alzheimer's begins with the accumulation of beta-amyloid plaques and tau tangles. Beta-amyloid plaques are aggregations of the beta-amyloid protein, and tau tangles are twisted fibers of the tau protein.<sup>7</sup> Accumulation of these proteins inside the brain's neurons blocks the transport of nutrients and other essential molecules.<sup>8</sup> This results in cell death, especially in the hippocampus and other regions of the brain responsible for memory.<sup>9</sup> The cell death in these regions causes the symptoms of Alzheimer's.<sup>10</sup> These symptoms include "aphasia (language disturbance)[,] apraxia (inability to carry out motor tasks even though motor abilities are intact) [, and] agnosia (problems in recognizing or naming objects)."<sup>11</sup> Moodiness, restlessness, delusions, and wandering are all common symptoms of the disease as well.<sup>12</sup>

Reading about how Alzheimer's affects the brain helped me feel prepared for the challenges my grandmother would face as her disease progressed and her mental state declined. However, I soon realized that symptoms of Alzheimer's are much more than just mental; there are several physical symptoms as well. Alzheimer's does not just eat away at one's memory, but at one's body itself. My popo, for example, now forgets to maintain the beauty routines that she once religiously fol-

3 "What Is Alzheimer's Disease?," National Institute on Aging, accessed December 3, 2017. <https://www.nia.nih.gov/es/node/20370>.

4 "What Is Dementia?," National Institute on Aging, accessed December 3, 2017. <https://www.nia.nih.gov/health/what-dementia>.

5 National Institute on Aging, "What Is Alzheimer's Disease?"

6 "2017 Alzheimer's Disease Facts and Figures," Alzheimer's Association, accessed December 3, 2017. [https://www.alz.org/documents\\_custom/2017-facts-and-figures.pdf](https://www.alz.org/documents_custom/2017-facts-and-figures.pdf).

7 Timothy Revett et al., "Glutamate system, amyloid  $\beta$  peptides and tau protein: functional interrelationships and relevance to Alzheimer disease pathology," *Journal of Psychiatry & Neuroscience* 38, no. 1 (2013): 6–23, doi: 10.1503/jpn.110190.

8 Revett et al., "Glutamate system, amyloid  $\beta$  peptides and tau protein," 6–23.

9 Revett et al., 6–23.

10 Revett et al., 6–23.

11 Soukup, *Alzheimer's Disease*, 4.

12 "Stages of Alzheimer's," Alzheimer's Association, accessed December 3, 2017. [https://www.alz.org/alzheimers\\_disease\\_stages\\_of\\_alzheimers.asp](https://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp).

lowed. How to dye her hair and put on makeup have completely escaped her memory. Even more concerning is her failure to remember to eat. Whenever my grandmother is hungry, she goes to the kitchen to make herself food. However, during the time that it takes for her to take out all of the pots and pans, she forgets why she is even in the kitchen. She puts everything back, finds something else to do, and skips the meal. As a result, my popo has lost much of her original body weight. Compared to her appearance before, my grandmother is now barely recognizable. Her thick, dark brown hair now seems thin and ashy gray. Her dainty cheekbones that once accentuated her heart-shaped face now seem harsh as her face hollowed. Her cheeks, once delicately powdered with a rosy pink blush, now seem bare, empty, and pale. She was always skinny, but now she seems to be a mere five foot, four inch skeleton of who she used to be. Not only are my grandmother's memories fading, but she is fading as well.

• • • • •

I sat on my popo's living room carpet, reading *Goodnight Moon* to my little cousin. My uncle, who lives with my grandmother, had just returned from his day at work and was also in the living room, sprawled across the sofa, watching television. My popo was busy cooking dinner for the four of us when she suddenly emerged from the kitchen. She asked across the living room, "Alyssa, today is what day? Sunday?"

"No, Popo, today is Tuesday."

"Ohh, Tuesday. Agh, my memory is bad. I forget everything."

She returned to the kitchen, and I carried on with my reading.

Soon after, my popo emerged once again. "Alyssa, what day is today? Friday?"

"No, Tuesday, Popo."

"Mom, you just asked her that," my uncle intervened.

"Oh, haha. Really?" My popo blushed as she attempted to laugh off her embarrassment.

"I'm sorry. I forget everything. I don't know why. I'm so sorry. I just forget everything."

• • • • •

My popo has always been well-aware that her memory worsened, but she has never known why. I once asked my mother why she had not informed my grandmother of her Alzheimer's. It turns out that she has, but ironically, my popo has forgotten. However, in this case, my grandmother's forgetfulness proved to be beneficial. The one time that my mother and uncles did tried to tell my grandmother about her Alzheimer's, she was completely devastated. She immediately thought of her cousin-in-law, who also has Alzheimer's. My popo sobbed, "My sister-in-law always complains about how irritating her cousin is. Now she's going to say the same things about me. Everyone's going to say the same thing about me. I don't want

to live if that's how people are going think of me. I don't want to live." My mother and uncles were eventually able to calm my popo down, and after a few hours, she had forgotten the entire conversation. However, ever since then, no one has ever mentioned my popo's Alzheimer's to her again.

• • • • •

"Ahh, long time no see!" my popo exclaimed to the waitress as we entered the dim sum restaurant. The waitress responded back to my grandmother in Chinese, and they shared a hug. They continued to laugh and chat as the waitress showed us to our seats, handed our menus, and filled our glasses with water.

"Do you know what you want?" I asked my mother. I looked up to find her staring at our waitress who was now at the table next to us, talking to one of the other waitresses.

"What did you say?" she replied, turning her head towards me.

"What are you looking at?"

"Nothing."

"No, just tell me."

"Our waitress is telling the other waitress about Popo."

"What do you mean?"

"She said that Popo is annoying her because she keeps repeating herself and saying that they haven't seen each other in a while. She said that they used to be good friends, but she stopped hanging out with Popo because she would always annoy her like how she is now."

"Oh. Does she not know that Popo has Alzheimer's?"

"I don't think so."

"Oh."

I watched my grandmother's eyes light up as the waitress returned to take our orders. She stood up and hugged the waitress. "Ahh, long time no see!"

• • • • •

The more my grandmother's memory worsened, the fewer friends she seemed to have. One day, my mother received a call from my popo, crying that none of her friends would hang out with her or even answer her calls. All I could remember was the way my grandmother praised these same people when I was younger. She always told me how fortunate she felt to have found such terrific friends. I wondered how these friends could distance themselves from my popo so quickly just because of her disease. Perhaps they truly were *that* irritated with my grandmother's repetitiveness, or perhaps they got freaked out by how much my grandmother's Alzheimer's was changing her. For the sake of my grandmother and the friendships she used to have, I try to believe the latter.

After losing the majority of her friends, my grandmother began spending most of her days home alone. Knowing how miserable my popo must be made me feel guilty for not spending as much time with her earlier in my freshman year. In an attempt to relieve some of her boredom, my parents and I have

started to invite my grandmother to more of our family lunches, school events, and even Costco shopping trips. However, with everyone being preoccupied with their own work, the bulk of my grandmother's time is still spent by herself. My popo's doctor suspects that this loneliness and loss of friends may have caused the onset of her depression. Unfortunately, depression and Alzheimer's is not an uncommon pairing. In fact, at one point or another, about half of individuals who have Alzheimer's disease will face symptoms of clinical depression.<sup>13</sup> For individuals who are aware of their diagnosis, depression can arise as a response to the alarming news of having Alzheimer's.<sup>14</sup> For others, depression can arise from family and friends' negative response towards their severe cognitive decline.<sup>15</sup>

• • • • •

It quickly became obvious that family is really all that my popo has. Because my grandfather and grandmother are estranged, all the pressure of caring for my popo has been placed onto her three children: my mother and her two brothers. My popo calls my mother every day, asking if she can buy her groceries, pick up her prescriptions, take her to doctor appointments, or simply keep her company. As a result, my mother frequently has to take off from work to help my grandmother. However, this time away from the office eventually catches up to her, and my mother is forced to stay up late at night, rushing to meet her deadlines.

Similar to my mother, my two uncles receive frequent calls from my popo. Because one of my uncles lives with my popo and the other lives five minutes away, they often help her with home repairs. From leaking faucets to faulty televisions, my uncles help my grandmother fix anything broken. My uncles also play a significant role in ensuring that my popo remembers simple things such as eating, locking the door, taking her medication, etc. However, in addition to caregiving, living close to someone with Alzheimer's is a difficult task in itself. My uncles are always answering the same question a hundred times a day and assisting my popo with the same requests. As one could expect, the stress of looking after my grandmother can sometimes become overwhelming.

This stress that my mother and uncles face is not unusual. In fact, around fifty percent of caregivers, family or professional, suffer moderate or severe negative health effects as a result of caregiving.<sup>16</sup> These symptoms include "depression, nervousness, anxiety, sleeplessness, frustration, and lowered

morale."<sup>17</sup> They are the consequences of the sacrifices that come with caregiving, such as "restrictions on time and freedom, interference with social and recreational activities, income, plans for vacations and for the future, privacy, and use of space in the home."<sup>18</sup> In addition to the toll of caregiving, family caregivers often experience an emotional toll as a result of their concern for the patient's health.<sup>19</sup> As seen in my mother and her brothers, all of these factors combined can place an immense amount of stress on caregivers.

• • • • •

As mentioned before, Alzheimer's is irreversible. It is a disease of waiting. There is no cure, so all you can do as a caregiver is simply wait for your loved one's disease to progress. You wait for the day they forget to take their medication and need you to start calling them as a reminder. You wait for the day they wander away from home, forget how to get back, and need you to start personally driving them around. You wait for the day they "pull the last string" by leaving the stove on overnight and prove that a care home is now necessary. You wait for the day you visit them in the home and learn that they have forgotten where they are. You wait for the day you visit them in the home and learn that they have forgotten who *you* are. You wait for the day your loved one's memory completely fades away, and the day that you realize that they have faded away with it. Then, finally, you wait for the day that you begin to fade away too.

Not only do Alzheimer's family caregivers face the stress of caregiving, but the looming idea that they, too, could one day find themselves in their loved one's shoes. If you have a first-degree relative with Alzheimer's, your chance of developing Alzheimer's rises from ten to fifteen percent to thirty to forty percent.<sup>20</sup> Although researchers have yet to identify which hereditary gene causes the increased risk, this statistic raises alarms for many.<sup>21</sup> As a result, family caregivers of Alzheimer's patients report three times as many stress symptoms compared to the general population.<sup>22</sup> Being a caregiver is difficult,

17 Light and Lebowitz, *Alzheimer's Disease Treatment and Family Stress*, 4.

18 Light and Lebowitz, 4.

19 Eve Wittenberg and Lisa Prosser, "Disutility of illness for caregivers and families: a systematic review of the literature," *PharmacoEconomics* 31, no. 6 (2013): 489–500, doi: 10.1007/s40273-013-0040-y.

20 Scott Roberts and Sarah Tersegno, "Estimating and disclosing the risk of developing Alzheimer's disease: challenges, controversies and future directions," *Future Neurology* 5, no. 4 (2010): 501–517, doi: 10.2217/fnl.10.31.

21 Roberts and Tersegno, "Estimating and disclosing the risk," 501–517.

22 Light and Lebowitz, *Alzheimer's Disease Treatment and Family Stress*, 4.

13 James Ellison, "Depression and Alzheimer's Disease," last modified November 14, 2016. <https://www.brightfocus.org/alzheimers/article/depression-and-alzheimers-disease>.

14 Ellison, "Depression and Alzheimer's Disease."

15 Ellison, "Depression and Alzheimer's Disease."

16 Enid Light and Barry Lebowitz, *Alzheimer's Disease Treatment and Family Stress: Direction for Research* (Rockville, MD: Hemisphere Publishing Corporation, 1990), 4.

but being an Alzheimer's caregiver has proven to be even more challenging.

Because of its negative consequences, it is important to learn how to cope with caregiver's stress. Realizing that you have caregiver's stress is an important first step to treatment. Feelings of being overwhelmed or isolated, weight change, fatigue, irritability, anxiety, and body aches are all early signs of caregiver's stress.<sup>23</sup> Once aware of your stress, recommended ways to cope include reaching out to other relatives and family members for extra support, setting a daily, organized routine with all the tasks that need to be done, and most importantly, allotting relaxation time for yourself every day.<sup>24</sup> For caregivers experiencing family tensions, seeing a "care manager" has become an increasingly popular course of action.<sup>25</sup> A care manager's job is to collaborate with the patient's physicians to determine the care they need and create a set plan that divides responsibilities among family members.<sup>26</sup> Finding ways to maintain the health of the caregiver and their family relationships is just as important as maintaining the health of the person with the disease.

• • • • •

Alzheimer's is extremely common, affecting one in ten people age sixty-five and older.<sup>27</sup> However, this statistic is rapidly growing, with someone in the United States developing the disease every sixty-six seconds.<sup>28</sup> More than five million Americans currently live with Alzheimer's, but by 2050, this number is expected to rise to as high as sixteen million.<sup>29</sup> As Alzheimer's disease affects more and more people, it becomes crucial that we learn the proper ways of caring for those with the disease while also still caring for ourselves. Even if we do not come across someone who has Alzheimer's, almost everyone, at one point in their life or another, will adopt some type of caregiving role. "Eighty-three percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers."<sup>30</sup> Whether it is for someone who has a simple cold or someone who is terminally ill, we will all find

ourselves responsible for tending to someone's needs. No matter how large or small our role may be, experiencing caregiver's stress is a possibility. This being said, it is vital that we know how to manage caregiver's stress and care for another without harming our own health.

As my grandmother's Alzheimer's progresses, my wish is for my mother and uncles to find a way to manage their caregiver's stress. With the help of my entire family, I hope that we will all be able to continue supporting my popo. My grandmother has always shown others nothing but compassion and kindness, so it would be wonderful to see her receive that same amount of love and care in return.

## Bibliography

- Alzheimer's Association. "2017 Alzheimer's Disease Facts and Figures." Accessed December 3, 2017. [https://www.alz.org/documents\\_custom/2017-facts-and-figures.pdf](https://www.alz.org/documents_custom/2017-facts-and-figures.pdf).
- Alzheimer's Association. "Stages of Alzheimer's." Accessed December 3, 2017. [https://www.alz.org/alzheimers\\_disease\\_stages\\_of\\_alzheimers.asp](https://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp).
- Ellison, James. "Depression and Alzheimer's Disease." Last modified November 14, 2016. <https://www.brightfocus.org/alzheimers/article/depression-and-alzheimers-disease>.
- Light, Enid, and Lebowitz, Barry. *Alzheimer's Disease Treatment and Family Stress: Direction for Research*. Rockville, MD: Hemisphere Publishing Corporation, 1990.
- Link, Greg, and Hepburn, Kenneth. "Caregiver stress." Last modified August 17, 2015. <https://www.womenshealth.gov/a-z-topics/caregiver-stress>.
- National Institute on Aging. "What Is Alzheimer's Disease?" Accessed December 3, 2017. <https://www.nia.nih.gov/es/node/20370>
- National Institute on Aging. "What Is Dementia?" Accessed December 3, 2017. <https://www.nia.nih.gov/health/what-dementia>
- Revett, Timothy, Baker, Glen, Jhamandas, Jack, and Kar, Satyabrata. "Glutamate system, amyloid  $\beta$  peptides and tau protein: functional interrelationships and relevance to Alzheimer disease pathology." *Journal of Psychiatry & Neuroscience* 38, no. 1 (2013): 6–23. doi: 10.1503/jpn.110190.
- Roberts, Scott, and Tersegno, Sarah. "Estimating and disclosing the risk of developing Alzheimer's disease: challenges, controversies and future directions." *Future Neurology* 5, no. 4 (2010): 501–517. doi: 10.2217/fnl.10.31.
- Soukup, James. *Alzheimer's Disease: A Guide to Diagnosis, Treatment, and Management*. Westport, CT: Greenwood Publishing Group, 1996.
- Wittenberg, Eve, and Prosser, Lisa. "Disutility of illness for caregivers and families: a systematic review of the literature." *PharmacoEconomics* 31, no. 6 (2013): 489–500. doi: 10.1007/s40273-013-0040-y.

23 Greg Link and Kenneth Hepburn, "Caregiver stress," last modified August 17, 2015, <https://www.womenshealth.gov/a-z-topics/caregiver-stress>.

24 Link and Hepburn, "Caregiver stress."

25 Alzheimer's Association, "2017 Alzheimer's Disease Facts and Figures."

26 Alzheimer's Association, "2017 Alzheimer's Disease Facts and Figures."

27 Alzheimer's Association, "2017 Alzheimer's Disease Facts and Figures."

28 Alzheimer's Association, "2017 Alzheimer's Disease Facts and Figures."

29 Alzheimer's Association, "2017 Alzheimer's Disease Facts and Figures."

30 Alzheimer's Association, "2017 Alzheimer's Disease Facts and Figures."