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"When you lose your mind, you lose your self, I would have said.  
Alzheimer's makes people into zombies, I would have said. The walking  
dead. Give me anything, but spare me this disease, I would have said."

-Lauren Kessler  
from Living in the Land of Alzheimer's: One Daughter's Hopeful Story

The squeaking door interrupts our silence. A short, balding man, no older than fifty timidly peaks his head in the room to survey the situation. Discomfort: check. Anxiety: check. Hopelessness: check. Despite the tension in the room, or maybe because of our apparent angst, the short man decides that we pass his test and clearly need his assistance. He soon saunters into our room, casually pulls up a chair, and sits right in front of me. A pretty bold move for a stranger, but his audacity doesn't end there. He briefly locks eyes with me while using the tone of an old acquaintance to ask how I am doing. My mind races over his facial features as I try to place him in my memory, but he disrupts my thought process as he repeats his question.

"How are you doing?"

I manage to mumble something in an effort to appease him, which apparently works because he nods his head, providing me with some time to mull over the more important question involving his identity. His white overcoat and clipboard distinguish him as a doctor. I discern that immediately, but I still don't understand why my own doctor didn't come to check on me. He must be busy with other patients. I turn to my husband to see if his reaction mirrors mine, only to find him with both hands strangling his flat cap, the rest of his body absolutely motionless. No longer staring at the floor, his gaze remains frozen on this short, strange man sitting in front of me. The little man doesn't acknowledge the stares but continues to scan his clipboard, loudly flipping through each page without looking up once. Since he hasn't said anything about the documents in his hands, I assume this clipboard came from my doctor and contains my medical charts, test results, and future.

While my husband tries to look over the doctor's shoulder to sneak a peak at the documents, I know that I don't need to see them. This doctor will only verify what I fear. I knew the diagnosis before I came here, but I couldn't cope with the thought. I knew others wouldn't be able to either. Therefore I decided that I couldn't and wouldn't. I couldn't bear to tell my husband, only to watch him struggle to contain his composure, to tell my friends, only to find them suddenly too busy for outings, or to tell my co-workers, only to discover they've lost their respect and trust in my capabilities. So I wouldn't tell them. I wouldn't hurt them. Admitting it would only cause overwhelming grief to everyone involved and I can't bear to lose them, their respect, or my composure.

Clearly I had no choice in the matter. Eventually I couldn't conceal it anymore, from myself or my husband. So we scheduled an appointment with my doctor, which lead to other appointments with psychologists and neurologists. Each visit left us uneasy and unsatisfied because the doctors struggled to characterize what my ailment was, let alone discover what caused it. And yet, relief built each time my fear wasn't confirmed. Not so lucky anymore. This doctor held the answer in his hands. The paperwork which decided my fate floated before my eyes, taunting me with each slow, deliberate turning of the page. It was only a matter of time before the doctor ended my misery. "Well," he said, raising his eyes from the charts and pushing his glasses higher up his nose, "you don't have a vitamin deficiency, mitochondrial disease, HIV, or cancer because your

blood work came back normal and your lumbar puncture was negative. Your electroencephalogram, or EEG, showed no new damage, but your magnetic resonance imagery, or MRI, had a mildly abnormal reading in the right temporal lobe. It appears as though you may have had a small stroke which damaged multiple quadrants of your vascular system. He pauses to see if I'm following him, but doesn't even give me enough time to take a deep breath, let alone ask what all this means. He continues, drilling home the message that I'm doomed, "we conducted extensive blood work, a brain scan, and other neurological tests to help rule out hydrocephalus, masses, cerebral vascular disease, and a number of rare conditions, but the tests' results suggest that you are living with

With her head bent down, one hand clutching her coat tightly, she leans against the door with her forearm and throws her weight onto the bar until it clicks and forces the door open. While straining to avoid moving her feet until the last possible moment, she surrenders and takes a step before losing her balance. Leaves crunch beneath her feet, wind blisters her face, and the door slams shut. No turning back now. She pulls her hood up over her head and steps out from beneath the protection of the overhang into the bitter rain. The soft drops pound against her body and trickle down her raincoat, momentarily hanging on the edge of the plastic before they absorb into her jeans. After a couple of steps her jeans cling to her legs, but she continues trudging through the shallow stream which was a cold metal ramp only yesterday. As she rounds the corner of the ramp and raises her head to see if her ride is waiting, she notices a girl with brunette hair several feet down the sidewalk decked out in rubber boots, long raincoat, and matching umbrella. The brunette doesn't notice the girl as she walks toward her, but raises her head, smiles, and waves as she hears her name.

"Hey Marie" the girl on the ramp says as she tries to shield herself from the rain by pulling her raincoat hood farther down her forehead. She brushes her hand across her moist bangs, tucking them deeper into the hood to prevent them from getting any heavier with rain, but her attempt to stay dry backfires as the water from her bangs trickles down her face and neck, dampening her sweatshirt beneath the raincoat. A shiver runs down her spine as she pulls the coat tighter with one hand and uses her other hand to weigh down her coat's hood. Drops of water hit her wrist and run down her arm, moistening the edges of her sleeves, but there's nothing she can do now. With her hood secured she quickens her pace and shuffles down the ramp finally landing on the pavement without slipping. The brunette faces the girl as the girl walks up to her and says, "What awful weather for our first day, especially since we don't know what to expect."

"Yeah. I'm glad we practiced a trial run though. I feel more prepared since we got to experience the process from each role."

"I'm still really nervous though."

"We'll be fine after our first time. I'm sure once we start, our nerves will fade, and things will run smoothly. You'll be fine."

"I sure hope so." The girl looks down at her watch as she asks, "What time did Sarah say she would pick us up?"

"She should be here soon. Don't worry it's not far, just down the road a little way."

They stand next to one another in silence watching the rain ripple across puddles. "I'm looking forward to this but I'm so nervous. What did I get myself into?" The rain hitting her raincoat's hood funnels into a little stream, dribbles in front of her face, and distracts her as she tries to remember what she was going to say. "We"...a drop splashes on her nose. "Hopefully we made the right decision. This is going to be intense and we

We conducted extensive blood work, a brain scan, and other neurological tests to help rule out hydrocephalus, masses, cerebral vascular disease, and a number of rare conditions, but the tests' results suggest that you are living with Alzheimer's disease."

He mentions my tests, but I can barely make sense of the words "blood test," "chemical profile," "lumbar puncture," "EEG," and "MRI," let alone understand what my results mean. My mind remains focused on "Alzheimer's." I expected it, but the diagnosis still sucker punches me, distorting my face and leaving me unconscious. I'm not physically passed out on the floor but I'm not coherent either. Even though I don't want to give up the fight, I can't gather the strength to shake it off and get to my feet. The referee stands over me, loudly counting. The bell rings. The medic rushes to my side and begins cleaning the blood off of my shoulder. I feel the warmth and gentle touch of my husband as he places his hand on my shoulder and begins rubbing my back. I can also hear his voice but everything remains clouded, distant, and indecipherable. He sits next to me, still rubbing my back, and places his other hand on my hand, breaking my trance. "What are her...what are our options doctor?"

The doctor begins telling me advice that I already know, "Well, Alzheimer's is a terminal illness which...blah blah blah." I drop my head and stare at my hands because I know what will happen, I know I will get to the point where I won't recognize my husband, where I won't be able to control my bowels, where I don't want to live but won't be able to recognize this desire. I won't be myself nor will I be able to care for myself. That burden will fall on my family or caretakers from some facility. "...forgetfulness, delirium, confusion, aggression..." He continues talking despite my incoherence, but my husband squeezes my hand tighter and nods his head to show that his advice isn't wasted. "...clinical trials you can volunteer for..."

"Clinical trials?" He grabbed my attention and lifted me off of the mat.

"Could you please repeat that? I'm sorry; this is just a lot of information to digest at one time. I always worried about it...about getting Alzheimer's because several members of my family suffered from it, but I never imagined I would get diagnosed at sixty-four years old." "I understand. Although awareness of Alzheimer's disease has dramatically increased in the last decade, society still views Alzheimer's as a disease of the elderly. The truth is that ten percent of those suffering

from Alzheimer's are less than sixty-five years old and experience this early onset form. You are still enjoying your life, which only increases the strain that this disease will place on you and your family. Unfortunately I can only recommend trying out a prescription to slow the progression of Alzheimer's, a prescription such as Aricept or Namenda, and, if you are willing, to volunteer to become a part of a clinical study of other Alzheimer's medications. While either decision contains risks, if you decide to try the drugs in clinical development, you can still take Aricept or Namenda. Johns Hopkins is currently accepting subjects to test their new drug MF 1231. The trial runs for a year and has shown promising results in previous testing, but you must remember that this treatment is a study drug that may or may not be beneficial for you and may or may not harm you. And you may even end up in the control group, taking a placebo. If you are interested in volunteering I can get you the paperwork to fill out to apply for the clinical trial."

Without looking at my husband I shake my head yes. "I would appreciate that."

"Are there any other questions you have about the disease, medications used to slow the progression of Alzheimer's, or clinical trials in general?" He pauses as I look at my husband and we try to decide which of our infinite questions we should actually ask him. "I'll go and get the paperwork for you and give you a moment to think about it." After he returns with the clinical trial paperwork and a prescription, he answers some of our questions before we leave his practice. When we reach home I immediately fill out the paperwork, submit it, and within the next couple of weeks I receive a

A drop splashes on her nose. "Hopefully we made the right decision. This is going to be intense and we need to expect the worst. She did say anything could happen and that something unexpected would surely interrupt the process." The girl shivers as the rain drops travel down her face and neck, seeking refuge in the collar of her sweatshirt. She zips her raincoat all the way up and tilts her head down to let the rain run off of her hood onto the ground while protecting her face from the cold wet drops. From a distance they can hear the car accelerating up the hill, but neither of them moves, neither girl wants to expose herself to the rain yet. So they stand there in

In the next couple of weeks I receive a letter of acceptance into the clinical treatment study group. Several more weeks of anticipation pass before my first clinical treatment, but when the day finally arrives I can't find the keys. My husband's aggravation grows as we tear apart the house looking for the last set of keys. "You just had them a second ago..."

"No I didn't. Why would I have them? I haven't driven in weeks."

"Why are you angry at me?! I didn't lose the keys. I'm not the one who moved them in the first place or lost the other two sets doing God-knows-what!"

"...but I have no idea where I placed them. Wait. I picked them up from the mantle but then you ran outside to move something in the yard. You took

the keys to go move something in the yard."

"What are you talking about?"

At a loss for words and tired of fighting she stumbles into the kitchen to get a glass of water. As she opens the cupboard to pull out a cup her hand encounters something cold, flat, and perforated. "I found them."

"Thank God. Where were they?"

They were right here next to the...right next to the... Well it doesn't matter. Here they are in my hand and we are running late for my first treatment. Let's get going!

He shakes his head, smiles, takes the keys and heads out to the car. Once they arrive at the designated outpatient treatment center, they present their insurance cards, fill out some paperwork, and sit and wait and sit and wait.

"Four."

A woman in floral scrubs with frizzy hair repeats again, "Number four?"

"Honey they just called your number. Good luck. I'll be waiting here when you get out."

I stand and follow the woman in floral scrubs. As we walk to a private room in the back the nurse says, "Now I'm just going to remind you of a few things. We will ask you a couple questions as a preliminary measure to track your progress throughout the course of the medical treatment. These are questions similar to the ones that your own doctor may have asked you last time you visited. Then I will secure an IV in your right arm and give you the meds intravenously. The whole process could take anywhere from one to two hours." We arrive at a room and the woman in floral scrubs enters and forcibly points to the hospital bed. I hop up onto it, making myself comfortable while the nurse finishes her instructions. "After your treatment is over we ask you to lie here for another twenty or thirty minutes. You can watch television, take a nap, read a magazine. We just want to monitor your immediate reaction to the injection and make sure that you don't pass out. It will be over before you know it." The woman in floral scrubs ends her spiel with a fake smile, which only makes me uneasy. She hurriedly shuffles out of the room, leaving me alone to contemplate my future life with Alzheimer's. What if I receive the placebo instead of the actual drug? What if I actually get the injections filled with the drug and it doesn't work, or even worse what if it backfires and increases the progression of my disease? The more I think about it in realistic terms, the less optimistic I become because I know the odds are stacked against me. Before I can deflate my spirits anymore a male nurse knocks on the door and enters. "Hi. I'm going to ask you some questions, set up your IV, then administer your bag of meds. Please roll up the sleeve of your right arm." As I roll my sleeve above my elbow, he asks me trivial questions, marks down my responses, and pulls out a rubber tourniquet, needle, and some medical tape. I can't bear to watch him inject the needle into me so

I turn away after he ties my arm and finds a strong vein. In seconds I'm hooked up, receiving my IV injection of MF 1231. I can sense the cool liquid flowing through my veins. Already I feel transformed, as if my Alzheimer's will slow down and maybe even stop, or maybe, just maybe I will be lucky enough to fully recover. As these thoughts run through my mind I look at the bag suspended above my head off to my right side. It's less than a quarter of the way full so

So they stand there in silence, waiting. As the car emerges around the side of the building, Marie starts to close up her umbrella and walk to the edge of the curb while the other girl shakes off her raincoat. The girl tries to occupy herself by pushing the leaves around with her foot, but in seconds the car pulls up to the curb. The girls reach for the door handles simultaneously seeking shelter in the confines of the warm, dry car. "Hey Sarah thanks for picking us up this week. I'll drive next week," Marie says.

"Yeah, thanks. I'm not gonna lie, I'm relieved that I'm not driving this week. I get nervous driving to places that I haven't visited before and I'm a mess as it is."

"I don't mind driving. I actually find it relaxing. I'm glad I didn't take one of the facilitating roles." Sarah continues driving straight across the bridge.

"Yeah. I think it will be better to watch other people and learn from their strengths and weaknesses before we have to go. Hopefully it will also get easier each time."

"We are just nervous now because we don't know what to expect."

Sarah makes a right hand turn.

"I'm sure everyone feels the same way."

Sarah turns left.

"We're lucky that we have become good friends. I'm actually surprised how close we became after meeting with each other only a few times."

"Was that it? Did we just miss the turn?"

"Yeah...that looks like it."

"She said there were big gates at the entrance and that's gated."

Sarah looks around and then backs up enough so she can make the turn. "I sure hope no one comes down this road right now because I

I look at the bag suspended above my head, off to my right side. It's less than a quarter of the way full so I sit back and relax. Before I know it, the treatment is complete, my waiting time has passed, and I'm escorted back out to the outpatient room where my husband has fallen asleep. I gently tap his shoulder and he jostles awake. "How did it go?"

How do you feel?"

"I could feel it coursing through my veins. The fluid was cool and created a tingling sensation every now and then, but all in all I didn't really experience any discomfort. I'm actually kind of tired. I don't think I'll have any problem falling asleep tonight." I smile. He laughs at my absurdity. "You never have trouble sleeping," he says as they get into the car. Before he leaves the parking lot he checks the traffic on his left then turns to the right to see if any cars are coming from that direction. He notices my head slumped against the window, mouth hanging open, and eyes closed. He smiles.

The next day I sleep until noon, which is unusual because I normally get up, have a cup of coffee, and read the paper while appreciating the quiet of early morning. I feel pretty good when my husband wakes me, so I decide to go for a run, but midway through the run I lose my stamina and any remaining desire to finish the workout. I lie down on a bench and take a nap. I wake up to my panicked husband. "Where have you been? I have been driving all over town for the past hour. You have been gone over two hours."

"I'm sorry. I thought I could get a good workout in, maybe run several miles, but I suddenly couldn't keep my eyes open. I fell asleep here. I'm sorry. I'll be more careful."

A week passed and I went for my second round of medication. A nurse asked me some questions, checked my vitals, and then administered the IV. Drowsiness overwhelmed me again, but I awoke to pain the next morning. The injection site on my arm was red, swollen, and tender to the touch. I called the outpatient center to see if I should come in for a checkup, but they assured me that tenderness often results from such procedures. After another week I went in for another treatment and told the nurse about my extreme drowsiness and inflamed arm. She wrote down the symptoms, checked my vitals, asked me some questions, gave me the IV, and sent me home.

Two more visits pass before I notice that my skin has started to thin. If I bump into something solid the contact, even if it's light, is almost guaranteed to draw blood. I can't even use band aids because the adhesive pulls off my flesh, making the wound worse. I relay this to the nurse the next time I visit, but she seems more concerned with my answers to her questions.

By the seventh visit I grow worried, because my green eyes have a yellow tint to them. The yellow eyes, coupled with the drowsiness, swollen arm, and thin skin, make me question why I'm still undergoing this clinical trial. They say that I can terminate my treatment at any time, but I can't. If I stop the clinical trial I concede to my fate, forfeit to Alzheimer's. Instead, I allow the doctor to examine me for Jaundice and check my vitals, but he finds nothing seriously wrong with me. I trust my doctor. He thinks I'm making progress with my memory because I can not only remember what I ate for breakfast a week ago or yesterday but this morning. Even my husband notices that I rarely put the keys in the cupboard anymore, experience less severe outbreaks of agitation, and no

longer get as confused when events interrupt my routine. But I don't see or feel any improvement. I think their hopefulness is impairing their ability to observe me objectively. Despite their optimism I'm still worried about the side effects, but they don't scare me as much as Alzheimer's does.

Before my ninth visit the doctor called me at home to ask me to come into the outpatient center to discuss my medical treatment. He wanted to share some news with me personally. So my husband and I, overcome with excitement, jumped into the car and drove to the designated outpatient center. When I walked up to the counter and gave the nurse at the reception desk my name, she phoned the doctor and had a nurse arrive immediately to escort me to him.

"What service! I guess he's really excited about my results. Do you want to come back with me?"

"Yeah. I just assumed I would, unless you don't want me to..."

"No. I think you should." The nurse didn't agree with me. She told me that my husband should stay in the waiting room, but I insisted that he come with me. I won; she caved. As the nurse escorted us to the back of the hospital, we passed the rooms where I normally receive my medical treatments.

"I wonder where we are going."

"No clue."

Finally, after walking through many wings and entering a locked down area, the nurse directed us to a room where the doctor was waiting for me. He told us to sit down. Nurses surrounded the door and began flooding the room. The doctor told me that I would no longer receive the treatments, because the doctors decided to terminate the clinical trial. Patients started reacting negatively to the test drug, so he told me that I would need to stay at the hospital under close supervision to make sure that I didn't also develop these same adverse side effects. He asked my husband to pack two weeks worth of clothes and return with them tonight or tomorrow morning.

"I feel fine. I don't think I need to be kept under close supervision."

"You do. We need to watch your vital signs."

"Can't I at least go home tonight and come back tomorrow morning with my suitcase. Spend one more night at home before I'm trapped here for two weeks?"

"No. The situation could get very severe quickly. We can't be careless. I can't let you leave. If you cooperate, you will make this much easier on yourself. If you refuse I will have to call security."

"Security? Doctor, really is that necessary? My wife will comply, but we still don't know what's happening. We appreciate that you want to do

what's best for my wife, but we're surprised by this news. We thought you were going to give us good news and tell us that the results of the trial showed great improvement in slowing down the progression of Alzheimer's and might even repair the damaged area of the brain. Why does she need to be locked down under twenty four hour supervision? Why can't she come home tonight?"

"I can't tell you the details right now, but I assure you that you won't be returning home tonight."

"Well why the hell not? Come on Honey. They can't hold us here." He grabs my hand and turns around to leave, but we are surrounded by nurses and security. Over a dozen people intervene, pulling my husband from my grasp as I scream and kick. They rush me to a room and inject me with a tranquilizer.

For the next month I'm in and out of consciousness. I have lost the ability to speak, open wounds cover my body, my eyes burn with a yellow brilliance, and my head slumps to my left side uncontrollably. The doctors ensure that my arms remain shackled against the bed at all times and they stay as far away from me as they can. Very rarely do people check in on me. They think I'm dangerous and won't even let my husband visit. He can only see me through a reinforced glass wall which encloses my bed. Despite their whispers and muffled conversations I discern the word "zombie."