

Don't Fall Mister

Do you remember the game, *Don't Break the Ice*? A red plastic man stands in the center of a floor of white plastic ice cubes. On the box cover are two little boys and the phrase, "The game begins, the ice is thin. Don't break the ice or you may go in."

Each player, an explorer with a yellow or green long-handled mallet—the goal is to chip out ice cubes without letting the red man fall through. Whoever lets him fall loses. But as long as there are a few pieces, strategically tight and balanced just right, the man can hold.

The pieces of white plastic ice fit so tightly together. You'd be surprised how many could be chipped away before the floor collapsed. Almost all of them, actually. But you knew that as each one came out, the foundation grew weaker and weaker. The odds that the man would fall increased every moment. For some reason, this game always made me anxious. When the pieces broke and clacked into a pile, the sound made me jump. Also, I didn't want the man to fall in, so I'd tap a single ice cube farthest away from him. Tap, tap, tap. "Don't fall, mister," I'd think.

I think about that game often, which is kind of surprising. After all, I played it in the seventies so it's odd it would ever cross my mind. But the image of the pieces there one minute and a gaping hole there the next have stayed with me. And the tapping.

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When I started researching Alzheimer's, I felt a little like an explorer myself. This was foreign terrain, and I only knew about articles I'd read as I scrolled through my morning news feed, or what I'd heard from people who knew someone with Alzheimer's, but now it was different because my dad had been diagnosed with it. Now I needed to really know more.

It was such an abstract disease. Memory loss was all I really understood: severe and debilitating memory loss, eventually rendering a person unable to care for themselves. I'd seen it with my grandmother, but only from a distance because I was young then and 3000 miles away. Soon, through both research and watching my father's decline, I'd come to learn a lot. Some things, I wished I didn't know.

Most importantly, I'd learn that Alzheimer's is the loss of actual brain matter and function that goes far beyond being unable to remember names or places or past events. *Loss of brain matter and function*—this was hard for me to process, to visualize.

I began to realize how powerful memory actually is. Because who ever really takes the time to consider the brain? We just accept that it gets us through our days and lives. But the brain and our memory inform and connect to *every single thing* we say, do, and think. They are responsible for linking words to ideas, interpreting pleasure or pain, recalling simple and complex information, and even, tragically, controlling something as essential as swallowing.

In my initial research, I came upon an image of a basic pie chart of how Alzheimer's impacts the brain. Imagine a full circle with pie pieces delineated as short term memory, long term memory, language, depth perception, motor skills, etc. As time goes on, in Alzheimer's patients, each piece of the pie slowly deteriorates. Short term memory goes first. Often language goes next. When a person can't recall a word, can't find it even though they've said it a million times, it is because the language center is deteriorating. As time progresses, more pie disappears.

This simplistic pie chart helped me understand what was happening to my dad. The progression of his disease was indeed just as the chart claimed it would be. First, I noticed him telling the same story three or four times over the course of our lunch. He told each rendition with the same level of enthusiasm, not noticing the confusion on my face—confusion I quickly

learned to mask. Interestingly, he remembered stories from when he was younger, like that time he hitchhiked from California to New Orleans and his mother busted him for it. Those were his long term memories, still intact for a little while longer.

Some time later, he couldn't understand how to sit in a car. He wasn't able to bend his body, duck his head, scoot back on the seat, and swing his legs over. Occasionally, he would fall trying to get in, even with us helping. You wouldn't think there were that many steps for a body to make to get into a car. This meant Dad's motor skill memory was going away.

I remember sitting down with a fresh notebook to read more about Alzheimer's one afternoon in July. Both the heat and the humidity were so high you'd break a sweat if you moved. The air conditioner made grinding noises outside my office window as it strained with the effort of keeping my small house cool. There, I sat and read up on the disease, made notes as if I was doing a research project. And maybe I was—the only research project that has ever mattered.

Not only did I want to understand Alzheimer's, I desperately needed to see if it could be slowed down. I knew I couldn't stop it or prevent it, but if I could figure out something, anything that could help my dad.... I compared his behavior to my notes to see how he was doing, hoping his disease was not progressing faster for him than the charts said it might. But what kept tripping me up was *how* exactly the disease could do this to a person. How could a person's brain essentially disappear? I couldn't fathom how it could impact some parts of the brain and not others. A pie chart wasn't cutting it; this research required a deeper dive.

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Articles on neurology, disease, and the brain are extremely difficult if you hadn't already guessed that. There was no skimming through this material. Now, as I read through websites,

blogs, academic articles, scientific research, I focused as though my life depended on it. Or my dad's life. I learned that there are genetic indicators that increase the risk that a person will get Alzheimer's. There are also environmental factors that contribute—diabetes being one of them. But what exactly happened in the brain?

As a result of either genetics or environment, there were these insidious plaque-like things called beta amyloid proteins and Tau that work together to gather between neurons, eventually interrupting cell function. I imagined Pac Man gobbling up dots but maybe it was more like the blob that grew and smothered essential parts of the brain. In either case, the brain takes a hit, piece by piece. The first part of the brain that's gobbled is the hippocampus—where new memories are made. And because it's also what controls how a person moves through space, damage to this section causes disorientation. Next in line is usually the hypothalamus. This is the hormone production spot—it's responsible for the brain letting us know when we're hungry, sleepy, thirsty.

The amygdala is an interesting little part of the brain. You'd think it was so tiny it might escape Pac Man's notice, but no. Shaped like an almond, it controls our perception of emotions. This part lets us know if we're feeling sadness, happiness, anger, love. When people with Alzheimer's begin to change personalities or become aggressive, it's usually because this part of their brain has deteriorated. The cerebellum determines movement and coordination. Once this is affected, a person has a hard time walking, their speech becomes garbled, and they have difficulty sitting up.

It was hard to believe that the brain, this mysteriously complex organ, could be attacked in such a methodical, persistent way. And yet, I'd known people who'd gone through cancer, so I

should have been prepared for the body's inability to fight disease. Any part of the body can decay, deteriorate, or be destroyed. Of course it could.

Another area under assault is the frontal lobe—the decision-making and planning center, which helps control impulses and emotions. Then, there's the parietal lobe, at the top of the head—the spot where pain is interpreted and information is processed. You'll sometimes notice Alzheimer's patients who are hypersensitive to touch or pain. For instance, my dad screams if you rub his arm with more than a feather's touch and acts like the shower is hundreds of needles coming at him rather than simply water. His parietal lobe has been chipped away. There's also the thalamus which is responsible for sleep regulation. In the beginning, Alzheimer's patients may be confused about when it's time to be awake or asleep. In the later stages, they will sleep all the time. Dad is only awake a few hours a day now. Lastly, the temporal lobe helps a person recognize everyday objects and hold on to new information. So they may no longer know that a toothbrush is for brushing teeth.

I studied this information and understood it. I did. Looking at my notebook though and looking at my dad—sitting next to him and watching him were two different things entirely. I could not reconcile them. Perhaps I was in denial, even after all of my research. My logical brain would not override my emotional brain where he was concerned. In his later stages, Dad forgot how to use a fork and began picking up food with his fingers. I thought, you know how to use a fork—you've done it for 80 years. Come on. Please. Pick up the fork. I wanted to cry, to hug him, maybe even shout at him.

Why couldn't he just do it? Oh wait. Now I knew why. I'd learned what the research said, what part of his brain had been affected and why. However, I never ran across anything that

explained what part of the brain is responsible for denial—when you cannot or will not believe what is in front of you.

Why is the brain so goddamn complex? I hated my own and I hated my dad's too. Because sitting there, feeding him lunch one day, I could not or would not process why using a fork was so difficult. It was just a fork and he'd been using one his whole life. He taught me how to use a fork for God's sake.

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Dad showed me how to make to-do lists when I was in my twenties. I'd just started working for him and he was all about them. He owned a small business—a bar supply company. They sold everything but the liquor, he'd say. I became well-acquainted with mixers—Bloody Mary, margarita, sweet and sour—styrofoam cups, olives, and sip stirs. You name it, we carried it. The company was called Pio Bar Supply, named after my brother. Neither my father nor my brother drank, so I'm not sure how dad landed on opening a company that serviced bars, but he did.

We sat in his office on my first day and he gave me the run down. His desk, by the way was not visible under all of the crap piled on it. He was a slob—I'll just say it now. Samples of three compartment trays were stacked behind him, invoices scattered all over his desk. Blue vinyl bank bags unceremoniously tossed on the floor. He cleared a spot on his desk and took out two fresh yellow legal pads. He gave me one.

“Here you go. This is the most important tool you'll ever need in sales,” he told me.

“A legal pad?” I asked.

“Yes,” he nodded. “That and your personality,” and he winked at me.

“Every morning,” he told me. “You make your list of things to do. It doesn't matter how hectic your day is or how little time you think you don't have. Do it. Trust me.”

He talked to me a while longer about goal setting and the importance of writing things down to be sure you remembered them. He explained planning and quoted Zig Ziglar, “Plan your work and work your plan.” Wearing a black Pio Bar Supply shirt, jeans, and a cowboy belt, he talked to me and you could tell he was excited to have me working with him. We were always close.

I remember him writing MONDAY in all caps at the top of his note pad and then he made a list of about twenty items. His pencil made soft sounds as it moved over the paper. I always liked his handwriting—box letters, big and bold, just like him. I wrote a few things to do on mine but nothing like his list. He sharpened his pencil, licked the tip.

“Let’s meet for coffee this afternoon and see how we did. 5:00 sharp.” Dad was sharp in all ways.

This sounded like a challenge to me, and maybe it was, but all I know is that I finished every damn thing on my to-do list. When we sat down for coffee and both put our tablets down as if we were showing a hand of cards, we both had every item lined through. Dad smiled at me. I’d done well, not just on my first day but at working my plan. Removing items off of a list, scratching them through—this represented accomplishment. Completion.

“Now you can start with a blank slate tomorrow morning,” he said.

To this day, I use a to-do list.

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A blank slate is usually good. Tabula rasa. Starting fresh. Except when it comes to memory—then it can go either way. Drawing a blank when you’ve had a long day is one thing. Having nothing where there once was something in your brain is entirely and devastatingly another. What makes it worse is that when parts of your brain are literally chipped away, you can’t get

them back. And, to date, there aren't a lot of options for compensating for such terrible loss. If you've lost a physical part of your body or some mechanical ability, huge strides have been made to compensate. For instance, if you are missing a limb, there are excellent prosthetic devices now. Hearing loss? State of the art hearing aids or cochlear implants are now available. For those people who can no longer use their voices, there is text to talk technology.

But if you've lost part of your brain, you're fucked. Brains cannot be reconstructed. Damaged or deteriorated parts cannot be revived. And because the brain tells the body what to do, the real, especially cruel, irony is that if you lose part of your brain, you also lose part of your body, or the control of it. In one fell swoop, they've lost mental and physical capability; the two are inextricably tied for those with Alzheimer's, so it can't be fixed or stopped. Because Alzheimer's is not a sexy disease, it doesn't receive the attention it should or the research dollars it needs. Even though around 5.7 million people had it as of 2018, at present, there are no cures, no repairs, and no real way to diminish its effects. If you have it, you can take only the few medicines that have been available for years—Dad takes Namenda and Aricept—to hopefully slow the progression of the disease.

Frustration abounds. The person who has it is angry at first, confused later, and blank toward the end. The caregiver is drained, exhausted, often helpless. Family and friends are upset and want to help, but how? Doctor's visits seem futile. It's like when you near the end of the game. So much ice is gone. The few pieces that remain are both pitiful and integral. You know the man is going to fall. You just don't know when.

A few questions are asked: What day is it? Who is the President? Reflexes and blood pressure are checked. No breakthroughs are ever announced. You leave as empty as when you came.

The painfully drawn out nature of the disease—to experience or watch—is perhaps the most frustrating. A slow-motion fade. I’ve never wanted to fill in, add on, bring back, or revive ever so much in my life.

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The Alzheimer’s brain does indeed do a disappearing act, one that can be researched and understood, but unless we experience it first-hand, it may never really be clear. In the beginning, I could see that dad was frustrated. He knew he was losing his memory and it angered him. Now, of course, he doesn’t know and it’s only hard for us, the ones who love and see him every day. As we see each new piece of him disappear, it’s heartbreaking. Oh we steel ourselves to be strong around him, but when I left him the other day, I sat in my car and cried for an hour because I understand that he has stopped walking and probably never will again. Those days are hard. Others are better.

Mom and I talk sometimes about how we were grateful for the parts of dad we have. Yes we miss him on an epic level; we miss the husband and father he used to be. *My friend*—I miss my friend too. There’s no getting round that Alzheimer’s is a crappy hand to be dealt. That it only gets worse. You never get better. *Ever*. As your brain deteriorates, your body shuts down until you are done.

When I tell people about dad, they get this sad look on their face and say, “Oh God, I’m so sorry. It sounds terrible.” I always say, “Yeah but…” and mention whatever thing I’m grateful for that he’s doing at the moment. In the beginning, it was, “Yeah, but at least he still knows my name and can talk to me about simple things.” Later, it was, “Yeah but he still enjoys his favorite meal.” And later, “Yeah he doesn’t know who I am anymore, but he smiles when I walk into the room.” Every “Yeah but” was a piece of ice not yet fallen.

I can't tell you how happy it makes me when I tuck him in for a nap and he winks at me and says, "Thank you sweetheart." Because he still sees me, even if he doesn't know that I'm his daughter or my name is Reine. He senses I'm a person who loves him. I'll take keeping that ice cube intact all day long because it means he's here now and he's holding. I haven't lost him yet. A lot is chipped away in Dad's brain now that he's in stage 7, but there is *just enough* to keep him from falling in, at least a little longer.