

Good morning, everyone. It's good to see you all, and I feel we're so blessed to be gathered again like this.

We haven't been together since November of 2019 when Chicago held its anniversary celebration. At that time, I was attending university to get my biology degree, in the hopes that I could one day go to medical school and become a doctor of palliative care. It was a big dream, but I was dedicated to taking those steps and seeing where I ended up. I thought, at the very least, if I followed my desire, I would arrive at a good place - a degree where I could help people, do science, and do work that fulfilled me.

This desire to become a doctor had started back in 2017, when I began to learn more about end-of-life decisions - something I'd already had some experience in. I had thought about it often over 6 years after the death of my best friend, Kevin "Kevo" Buck, to a car accident on November 26th, 2010. Suddenly, his family was faced with difficult decisions, and being so young, he'd never really talked about his end-of-life wishes. However, I knew what was meaningful to him in life. His father ended up pulling me aside, and asking me a very heavy question: should we let him go? He was in a coma at the time and the doctors weren't sure that he would make it due to his brain damage, and if he did, he wouldn't be the same. He would very likely be unable to walk, have any independence, think the same way, speak properly. I knew Kevo very well, his dreams, his personality, the things he valued and cherished in life. And I knew, with all my heart, that he wouldn't want to live like that, even if I wanted him to wake up. In that moment, Kamisama and Kevo were telling me the answer. I told his father without hesitation:

"Even if there was a chance, he would reject living like that. His freedom is paramount. We can't tightly hold on to him, no matter how badly we want him back." I didn't realize how much this moment of clarity would have an effect on my life.

Kevo became a precious mitama sama for all of us - even to people he never knew, saving their lives with organ donation. My friends and I did many things to honor his memory, including getting stickers of a KB that we took everywhere and pasted in places to show "where he'd been." His father enjoyed seeing us grow and live as much as we could in Kevo's honor. He also swore many times that Kevo made visits to him in very obvious and specific ways. Although it was so hard to lose him, and the grief stays with us, I am still wholly convinced that the right thing was decided then. Modern medicine is wonderful, amazing scientific advancements made in great strides. However, it can't fix everything. I didn't realize then, but I was making a palliative care decision with Kevo's father. I was honoring quality over quantity.

In 2017 I was spending time as a housewife really, taking care of the house and spending time as a moderator for a very niche roleplaying video game server called "Space Station 13." In that game, everyone can play a profession to make a space ship or station run fluidly, and funnily enough, all the characters I played were doctors, nurses, or medical chemists. The same thing often happened when I played any game, always playing an herbalist or a healer character. I suppose it had always been obvious that helping people was something that I was drawn to.

Another thing I liked to do in my free time was watching Frontline documentaries on the PBS website. I learned so much from them. But one in particular changed my life. Titled "Being Mortal", the documentary was based on the book of the same name. The documentary talked about the topic of end-of-life, palliative care being a rising movement, and matters surrounding such things. Direct and unapologetic, the doctors in the documentary stated firmly: medicine is amazing, but we were reaching a plateau. People are dying in pain because of the mindset of "Do anything to keep them alive", losing **quality** of life in exchange for **quantity**. Instead of fearing death, we needed to begin to face it honestly, knowing what we wanted, knowing what our dreams were, knowing what "life saving measures" meant... if we were willing to endure the pain of such measures to give us a shot at having more time, or if we were willing to exchange that quantity for comfort, peace, and the ability to speak with the people we loved. I was inspired by this area of medicine so much that I watched this documentary **three times**, trying to understand what it was that was stirring in me. There was a certain doctor in it that was my inspiration - Kathy Selvaggi. When she was introduced, my mind was saying, "What if I could be like her?"

KATHY SELVAGGI, M.D., Palliative Care Specialist: First of all, I think it's important that you ask what their understanding is of their disease. I think that is first and foremost because, oftentimes, what we say as physicians is not what the patient hears. "And if there are things that you want to do, let's think about what they are and can we get them accomplished."

Dr. ATUL GAWANDE: You know, people have priorities besides just living longer.

Dr. KATHY SELVAGGI: Yes.

Dr. ATUL GAWANDE: You've got to ask what those priorities are.

Dr. KATHY SELVAGGI: Yes.

Dr. ATUL GAWANDE: Then you've got to tune the treatment to those priorities.

Dr. KATHY SELVAGGI: Exactly. And if we don't ask and if we don't have these discussions, we don't know.

She moved me. I wanted to be able to help someone in the way she did - help them realize how important was to consider death as a piece of one's life. Maybe I could become a doctor.

At that time, I wasn't sure I was able to do it. I remember when I told my husband about my dream, I cried, because I knew it would be hard, expensive, and maybe impossible. They were tears of fear and happiness. The only thing I could think was that if I tried, Kamisama would help me and at least guide me to where I was supposed to be. The first thing I did in my inspiration was volunteer at the local hospital. It felt nice to be in that environment, inspiring in a way. Talking with patients was meaningful and it was nice to be able to give them small comforts where I could.

In 2019, around the time of the anniversary Taisai, I was in the thick of it. It's funny, if you go back and look at the pictures, one day is school materials, the next is the Taisai, and right after is pictures of Organic Chemistry notes! I had won a scholarship to my university, but I had to maintain, essentially, perfect grades to keep it. It was around that time that it was discovered that I had narcolepsy, a disorder where one's circadian rhythm is no longer functional, and a person can enter REM sleep at any moment. A teacher noticed it when I was asleep but still taking notes! It was also around this time that I began to research more intensely what being in medical school meant, what it took to make it and not fail. What I saw made me nervous. The level of competition was mind-boggling. Essentially every hour of every day was spent studying. The average student loan was as much as a house, and people had to live on those loans. The medical test to even be considered by schools, the MCAT, was 6 months of study alone. Not to mention the **quality** of medical students' lives is abysmally low - ask medical students! Mental illness is rampant, depression and anxiety is so high that mental breakdowns are common. Some schools have had to put up barriers in some parts of the buildings because of how often students jumped out windows, off of buildings, or into high speed traffic areas. I thought, it was already so difficult to maintain the level of dedication that I did, and the expectations of medical school was **double** the workload of what I was doing right then! I wasn't sure if I'd be able to handle medical school **mentally or physically**. However, I decided that I would keep pushing to try. After all, what could I say if I didn't even try?

Then, as we all know too well, COVID came into our lives, and the pandemic changed everything. Right in the beginning of my last year of school, this massive upheaval. Now to be clear, I was the type of person that always woke up very early and went to school of my own accord to use the quiet morning hours before classes started to do homework and study for tests. Suddenly, I couldn't do that any longer, and if anybody who has ever struggled with ADHD knows, routine is key to success. Now all routine was gone, and I wasn't even sure if I was going to graduate! However, Kamisama blessed me with professors who advocated for me, and helped me endure.

Another thing that happened due to the pandemic, however, was a sudden, intense honesty all over the internet from doctors, medical students, and medical professionals. When I was reading about all this, I really, truly wondered: if I had been in their shoes right at that moment, could I have done it? The answer every time was no, because more and more, the pandemic, and in it I felt Kamisama too, was training me in understanding what **quality** of life meant.

The one thing during the pandemic that we were allowed to do at school was come into the lab to do independent research. So when the time came for me to propose a project, I wasn't really sure what I would do. However, I understood about myself that doing something meant learning it more completely. I had struggled in my genetics class a bit, and so I told my mentor that I wanted to shore up my weakness in that regard with my project.

"Well, do you like plants?" She'd asked me. "Well, sure, but I haven't taken any classes about plants my entire degree."

"That's fine. I think you can pick it up."

And pick it up I did. Going into the lab, getting out of the house felt like such a blessing. I loved being there. I thanked Kamisama for that time. When I thought about the work I was doing at the bench, I remember thinking, "You know, I could do this sort of thing for the rest of my life and be happy. I love working on these plants, and I love learning so much about them." I sort of had a realization at that moment that this was what it felt like to "Be one with Kami" in the divine reminder. I felt joy, peace, gratitude, and care for the work I was doing. I always pray the same way to Kamisama - I make my request, but I always end it with, "But you know what's best, so please help me achieve what you think is best for me."

At first, I wasn't really sure how this could help people - it seemed really far from the dream I had set out for myself but I figured out what I wanted to do. I wanted to be a plant scientist.

Still, despite being successful and finding something that really fulfilled me, even working on technologies that would help people in the future - I still couldn't forget my dream. I supposed I would never achieve it. It felt a little embarrassing that I didn't make it, and though I didn't feel like a failure (after all, I set out to get a degree and got one), I still wondered if my passion was really just some misguided illusion. I was sure a lot of people were probably let down that I wasn't pursuing this goal of medical school. Still, I never regretted it. I trusted that I was in exactly the right place, because I'd prayed and followed what I felt Kamisama's signs were. At that time, I feel Kamisama knew

something that I didn't. Funny enough, there was one person in my life who thought that the medical school thing was a bad idea for me, because she thought I wouldn't be very happy doing it - my Granny. She never rejected the idea, but I remember how she said she was relieved that I wasn't going away to medical school somewhere else, and was doing interesting, fulfilling work right here.

When I had learned about palliative care back in 2017 and began to understand more about it, one of the first things I did was have a conversation with my grandmother about her end-of-life wishes. I was always very close to my granny, so we always had these kinds of candid conversations about anything.

She told me everything, every detail. She had a lot of wishes, and knew exactly what she wanted. I carefully wrote them all down and stored them on a document that I could access on any device - just in case.

She then said to me, "You know, you are the first and only person to have ever asked me this. Nobody's ever tried to have this talk with me. It's like they think I'll live forever, but I won't. I'm getting old. I'm just really grateful you asked, honey. I really feel like you care."

Even more, a couple years later... she made me her Power of Attorney, saying, "If I'm ever stuck in the hospital, you know exactly what to do." I felt deep gratitude for her trust, and great responsibility, too. At that time, I was still thinking I would become a doctor. Funny enough... if I had ended up in medical school like I had hoped, I would have missed a very crucial moment.

In April of 2022, my granny was suddenly hospitalized after what was supposed to be a routine visit with her heart doctor. Her heart was weak. She had felt out of breath, but wasn't entirely sure why. The medication she'd been on for 30 years started to fail, and so they started her on a new medication and even though they were certain she needed a pacemaker, it was required that they send her home with a "Life Vest" on her for at least a month, a device that was worn 24/7 and would restart her heart if it stopped. I think they failed to really recognize the stress she was under due to the new medication and this vest, because when she returned home that night, she had a heart attack that left her very weak. Returning to the hospital, they worked to get a pacemaker in her right away. However, I started to sense something wasn't right about all this. A heart attack, I knew, was damaging. People took a very long time to recover from it, and she was 87, meaning it would only be a very long, tiring process for her.

After the surgery was completed, I asked to be called right away as soon as she was in the recovery ICU. When I arrived, I immediately was met with a very difficult sight that brought me to tears. She was being intubated - put on a breathing tube - and she was struggling a lot, looking like she was being choked. I knew that was the reality of a breathing tube from my research in palliative care - no speaking, no breathing for yourself and feeling you have to entirely give up your breathing to this machine. Not to mention the bruising and pain it causes in the throat. She'd been on it once before after her bypass surgery, so she knew the drill. Luckily this time it was only for one day.

The next day when she was off, she looked at me and said, "Honey, I can never do one of those things again."

And I reassured her that she wouldn't have to.

The week that went by was difficult. She wasn't getting better. She kept saying, "I don't know, my heart has been working hard for a really long time and I don't think it wants to keep going much longer." And that was true. She wasn't healing, or taking to any of the medications. Her stay was getting harder - she was only getting weaker, and I was spending 16 hour days with her near the end because I hated the idea of her being alone. Still, she was lucid, chatting happily about memories with Patrick and I, telling me her favorite songs and the poem she would want at her funeral. She talked about her fears, hoping that god would think she was a good person and would accept her. We talked openly about these things, and she had me make the call to everyone and let them know to come and see her before the end.

Near the end, the doctors suggested one final surgery to see if something could be done. She asked if she'd have to be put on the breathing machine again, and when they said yes, I'll never forget the way she grabbed my hand and looked at me and said, "Honey, don't *let* them put me on that thing ever again. I won't do it again."

I reassured her that she *wouldn't* do it again, and said to the doctor that I didn't think another surgery was a good idea - that her quality of life was most important right now, and this just seemed like a futile effort to prolong the inevitable. He agreed, seeming almost *relieved* that I'd said that. This man had been my grandmother's heart doctor for 40 years. He told her it was an honor to know her, and they said their farewells.

However, I didn't realize at the time that that moment wouldn't be the actual test. I prayed sincerely to Kamisama that I was making the right choice in advocating for my

granny in this way. Every time I wondered, Kamisama always blessed me with an answer like that.

The last two days was perhaps the biggest trial but I prayed and prayed. Family showed up to see her, and she was alert and lucid enough to speak to them all. If she'd gotten that second surgery and been on the breathing machine, I knew she wouldn't have had these moments because her voice would have been taken away from her. I remember how she asked me not to leave - it was the Saturday night before mother's day, and she said she really didn't want to be alone. I knew these things were going to rely on the mercy of the ICU staff, since they didn't usually let visitors stay past 10pm. I prayed the divine reminder before going to the desk and explained my grandmother's request. One of the nurses said, "You've been such a huge help, and this is important to her, so I think we can let you stay." They managed to pull together a makeshift bed for me, and I laid next to my grandmother that night, holding her hand for much of it. She just wanted to know that I was there.

When her caretaker, and my mom's friend, showed up early on Sunday morning to spend time with my granny and do her hair for her (my grandmother was always very insistent on having her hair done and looking nice), she told me to go home for a bit and get some sleep. However, that was where the test really began. Once I left the hospital, my aunt got wind of this second surgery idea, and started demanding that *everything* be done to potentially save granny's life. The caretaker called me, scared for what was going to happen since my granny had been convinced that it "wouldn't be right" to pass

away on mother's day of all days. With only an hour of sleep under my belt, I had to drive back to the hospital to start advocating for my grandmother's comfort again.

My aunt and I are close, but we argued a little bit. I was so exhausted, and I didn't know what to do. It felt like I was being overruled because I was younger, and my aunt thought I was being rash, even though I had spent so much time with my granny and we'd come to this conclusion together. I remember feeling weak in that moment, unsure of what to do, so I just prayed to Kamisama that the right thing would be done...

And at that moment, my granny's renal doctor showed up. She was a stern little woman, but I had talked to her a lot through this whole process and was very grateful for her direct method of speaking - granny was too. Essentially, the medications keeping my granny alive in the ICU were damaging her organs, specifically her liver and her kidneys. According to this doctor, their function was basically gone at this point, and even *if* my granny lived through her second heart surgery, she would have had to have dialysis every day for the rest of her life.

So, this doctor appeared like an almost wrathful angel and spoke to my aunt. She told her, "People make this mistake too often, and I have to watch it. She's lucid and awake and comfortable right now. You will lose that, and so will she, if you go through with this. Her life will never be the same. It will be painful. You might take a shot at getting more days, but what kind of days are those? I can tell you, not good ones."

Quality over quantity. Hearing it from a professional, we thanked the doctor and she walked off, and I desperately thanked Kamisama.

Returning to my grandmother's room, I talked to her about what the renal doctor told us and she said, "She's right. She's always been very good to me. I don't want dialysis or anything less than what I had before. But... it's mother's day."

And I said, "Yeah granny, it's *your* day. You get to be selfish. You can do whatever you want, and we can't say nothing about it."

She teared up and smiled to me and said, "Yeah, you're right. I'm tired. I need a rest."

When they took her off the medications about an hour later, it was entirely peaceful. She passed so quickly, it was like she just went to sleep for a little while and slowed down more and more. She took one last breath, and we were all there with her. It was exactly how any palliative care doctor would have envisioned a "good" end.

Around the time before the very end, I'd asked a nurse about her vitals and he took me aside to show me his screen. During that time he said, "By the way, thank you for advocating so strongly for her. I've seen a lot of people die here, and I've seen a lot of people make extreme decisions that only caused a lot of suffering because they don't know what 'do everything' means. You know, you did the right thing for her and she gets to go so peacefully because of it."

I think I realized at that moment that Kamisama had helped me fulfill my wish - not in the exact way I'd imagined, but in a way that mattered deeply to me and my very beloved Granny. I prayed and prayed for Kamisama's 'nariyuki' (outcome of events) to become true, and when you look to Kamisama, I believe strongly that any wish you make, any

request that you have, will indeed come to you. Maybe not in exactly the way you envisioned, but Kamisama knows better. That's why the 'Divine Reminder' is called 'Divine Reminder'! It's always there to remind you of exactly a person needs to establish a wagakokoro in this life - a heart of joy and peace. I don't need things to go exactly as planned - I just need Kamisama's arrangements. Then everything will fall into place.

Thank you very much.

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