

My journey with the dreaded ALS [shorter condensed version.]

As early as 2010, my left hand was noticeably weaker. Doctors at Kaiser hospital performed tests and suspected brachial plexus damage. Then the following year my rotator cuff went bad. Hmm.

I kept taking care but no improvement. By 2014 started falling off my bicycle, and I noticed at the end of a day of teaching that my voice was warbly. Hmm. Disturbing, I went to get checked and this time they suspected a virus, so they gave nasal steroids. This didn't help.

2015 I went to Kaiser San Francisco for comprehensive neurological testing, hooking me with wires that when amplified gave loud static. The doctor decided it was ALS.

That felt surreal to hear. Doomed, but as the doctor pointed out, it's unknown how it will progress, everyone is different, but told me that it's fortunate that I'm starting this with top health. To keep up with my vegan diet.

I continued to do what I still could do, with slow progression. I think I did well for years, living with debilitating abilities in slow motion. My voice could not properly teach class anymore by late 2016. I switched to online teaching from 2016 until June 2020.

I started needing a walker in 2016. Fundraising was started by my brother Brian because I couldn't handle working more than two or three hour days. I still drove until early 2018. By then the local ALS group connected me with a loaner power wheelchair from the MDA, that became my car! I rolled all over San Rafael until 2020. I spent more time at Terrapin Crossroads, for live music and socializing. Thriving on being able to dance by holding on to sturdy railings. I am convinced that activity added years to my life!

In 2019, Kaiser Marin secured this Tobii Dynavox eye tracking technology I'm using right now!

Unfortunately symptoms worsened during the infamous pandemic year of 2020 and the state declared that I can't live alone anymore. I had been on lists for disability housing for years by then with no response. But nursing homes? Sounds like a nightmare, but necessary by then.

The hunt was on. My concerned family members in Seattle found an opening at a reputable nursing home. It was extremely tough leaving my home area for over thirty years and I wanted to die. Feeling like a prisoner in a strange land. I've faced much

challenges here, but still alive beyond 60 — against the odds.

Meanwhile my music interest keeps me interested in staying alive. Writing projects are important, and reading books on the Internet Archive, and very essential is curating my enormous collection of drawings — doling out my many sketchbook drawings to friends, framing with the help of the resident artist here in this nursing home.

It's all about making the best use of my severely limited lifestyle, and y'never know what might be ahead. Fortunately I have a strong will to have a good life, with a mind that comprehends. For now.

- Dean Gustafson, 2024

(with a much longer, more comprehensive version to post soon.)