

My journey with the dreaded ALS

2010-2020. Via 2024 (the long chronological version)

As early as 2010, my left hand was noticeably weaker. Doctors at Kaiser hospital performed tests suspected brachial plexus damage. Then the following year my rotator cuff went bad. Hmm. From bike accidents? arthritis? At any rate, it was a slow decline in my left hand for a few years to the point where my grip went bad, and I couldn't form a bar chord on the guitar, or do a decent drum roll anymore.

2012: I somehow gained a painful, pinched rotator cuff tendon in my left shoulder, preventing me from moving that arm much for a year and a half. This lack of mobility further slowed the flexibility and strength of my left hand.

2014: I wanted to get better and have a functioning left hand, so I went to a network chiropractor who was convinced they could help, so I signed on for a half year program. And while it was good for my overall spine health, my hand remained slow and weak.

I kept taking care but no improvement. By Summer 2014 started falling off my bicycle. I dismissed it as mere clumsiness, but by Autumn I noticed my left foot dragging a bit while I walked. I usually am a lightning fast walker, passing everyone by, but not anymore. Furthermore, I noticed at the end of a day of teaching that my voice was warbly. Hmm. This vocal and leg ailment was weird and disturbing, so I decided to finally get health insurance, through Covered CA for Kaiser, so I could get properly checked out. For my drunk sounding voice I went to get checked and this time they suspected a virus, so they gave nasal steroids. This didn't help. Still I seemed fit at 51, riding up the steepest streets of San Francisco with more ease than as 30! So what's the deal?

December 29, 2014: On one of my favorite Marin hikes near Fairfax, loving every step until I had to get back to the car by dark. On a slope rapidly pacing downhill, my shoelaces clumsily snagged too closely together and I took a violent tumble. This would never happen after many years of aggressive hikes, so it was the weaker left foot dropping that must've caused this. In horrible knee pain, I hobbled back to the car, and even managed to get new, better hiking shoes at REI on my way back home, thinking it was the fault of the boot design I was wearing.

When I get back, the next day my roommate Roberta in SF, told me I had to move out so her boyfriend could move in. ARGH! I could understand them needing to live

together and all, but break it to me so near New Years Eve while I'm disabled by injury? This with a torn meniscus in the knee. I couldn't walk.

So, a rotten new year, and my knee hurt too bad for me to attend the Flaming Lips show I had a ticket for. Bummer! I went to ER, and they gave me a cane and crutches.

2015: I am looking for an apartment in my favorite area of SF, the Inner Sunset, where I had been really enjoying living at in a solid old Victorian.. but no way could with these new prices, so I set for the east bay, where I have good friends. I found my own large apartment in the Temescal neighborhood, moving in mid February with generous help from friends since I could barely move.

April 2015: I finally had my appointment with the neurologist confirmed. He did some tests, and said its looking like a neurological problem, but needed more involved tests to find if it's a virus ..or something more serious.

I also discovered that I could no longer ride my bike, for safety of not falling off. When I could ride for just a few blocks, my leg would shake so rapidly that I could not dismount without literally crawling off the bike. Bad news for the devout bicyclist. I was seriously bummed.

May 20, 2015: the big tests, after an MRI and blood tests, with EMG —electrodes hooked up to my nerves. It was like they were tuning into Dean radio waves, to sounds of all static. I felt like I was tortured in a sci-fi scene. Increasingly, the Doc looked worried, until he had to break the news that all of the signs of ALS are there.

Surreal as it all was, I instantly told the doctor that he's doing a great job, and it must be hard to break news of such a heavy diagnosis. I had become suspicious that my hardcore vegan/veg diet was a contributing factor, but after all of the tests, the doc confirmed that its not the case, and that I've been doing everything right. Aside from the ALS, they said my health is up at the very top, which helps everything.

Walking out of the office, my mind was numb, but my leg was shaking like a motor. Emotions must be manifesting in those nerves. Freaky and disturbing. My good friend Joe gave me a ride back, and it was no fun for him to hear this harsh news. I was in cynical joke coping world though. Talking of being just a Stephen Hawking wannabe. Well, what to do but joke? This is not my year.

I instantly have a visit from brother Brian, bless his kind and concerned heart. He was truly shaken by my diagnosis. We got out and had some great local outings!

Summer 2015

Joni soon also visited! Amidst the good outings that we had, was going with for a 2nd opinion through a Marin neurologist who had extensive experience with UCSF's ALS program. The ALS verdict was undeniable. Hope was lost.

Now the news is spreading amongst family, friends and colleagues. I still signed up for teaching classes, but had to really work my voice more than ever to sound clear. Eventually I had to break the news to the Academy and my students, who are supportive and understanding. I was still walking 3 miles a day on average.

July

Good longtime friend Jamie and his wife Althea visit! We got some nice outings down the peninsula, including a Phish concert! Good times!

Soon after, Craig and Brian both visit! Memorable, fun times with the bros. Wonderful opportunity for a last bash around town as us three. [see my essay on summer 1984] We hit the old haunts at Ocean Beach, and North Beach! The huge Turner exhibition at the De Young museum that season was a great highlight we enjoyed! I went 10 times that summer! In North Beach we lived it up, dining at Caffè Puccini! Great week!

Brother Gary visited for a trip to Yosemite with my big handmade telescope! I'd been eager to share the astronomical experience with him, as a deep space enthusiast far before me. It was tremendously satisfying to join a star party with the San Jose group who welcomed participation, and some of us knew the same people. Like Dobson of course. Gary loved it, with superior views of the summer night skies than far north Alaska.

August

Anthony visit with plans for astronomy at Lassen Park! Local friend Rango joined, for a fantastic weekend with strong dark skies! I took my very final mountain hike on that trip. The rt walk to the geysers of Bumpass Hell and back, slowly with a walking stick. On the next night at the Devastated site parking lot for astronomy, I went to the restroom in the dark. Returning, I fell over and hurt my knee. The shaker was noticing my head was inches away from a boulder! So that could have been a medical emergency, out in the middle of nowhere. Yikes! Otherwise it was a great astronomy trip, and among my last.

Back in the bay area, we enjoyed a Phil Lesh concert, and SF, the ocean and the Turner show again!

Fall 2015: After a few falls and injuries, I have to use the cane when I hobble about over sidewalks. I compare my movements to using remote control to move my robot body properly. *Signal, bump in sidewalk ahead = Lift leg inch higher. Next, turn left: rotate right foot first, then left, then move forward at slow steady pace until the curb drops.* It's relearning how to move properly, it's all mind over matter, but does get wearying.

On the BART or bus, I need to ask for the disabled seating every time now. I cannot stand on a moving vehicle anymore. My hands can't grip the railing fast during a jolt, and my legs drop out to a surprise motion.

The neurologist wrote a letter recognizing that I should only work 3 hours per day (oh the irony, I always wanted more and more hours! I love my livelihood as an educator). So by then I'm signed up and ok'd by the Doctors for disability, but not yet, and am in that crossroads of still working 3 hours per day, which I want to continue doing but interferes with having enough income to survive on. I expected to maybe find a position where I can do online teaching and not have to speak. Quite frustrating, as I prided my ability to articulate. This also includes mourning the loss of my singing voice. It's all down to having new limitations.

The losses:

- Riding a bike. I rode all of the time, for decades. Everyone knows this about me. I was a badass hill monster. and I mean, we are talking about the steepest hills of SF and Marin!
- Speech. Perhaps the most frustrating of all. It threatens my career as a teacher the most, I sound like a drunk idiot. plus, singing is gone.
- Hiking. I still could then to a degree, but not on those technical trails I lived for. Walking I still could with a cane, steadily on flats and uphill, but not downhill or downward slopes. Bumps can be treacherous.
- Music. Drumming, I could still do, simply! but just not as technical, limited to no drum rolls. Guitar playing has gone downhill. I used to arpeggiate rapidly, learning Kottke material on the 12 string. That's all gone now, plus playing bar chords.
- Carrying things. I have to be very careful, as I fall easily. Moderation is okay, but I now need help to move my homemade telescopes around.

It's weird, but in 2015 I could still do around 50-70 push-ups, but barely button a shirt or open a jar. I could still draw and paint though!!! Thank heavens for that, but between

that and walking, for how much longer? A lot has diminished in less than one year by then, so I worked to preserve what I had. Art, Music, friends, teaching, astronomy, the natural and urban delights of the bay area, .. it all keeps me going. Otherwise, I am overly characterized by loss.. and that's no fun.

Nov - December.

Dhaivyd visits! We attended the Dickens fair! The remainder of the semester teaching part time, my seasonal enjoyment had been sketching at the Dickens Fair every weekend. I am grateful that I could still attend, with cane, and moving slowly. But could still stand and draw! I am seized the days while I had the functionality for them. Plus, I just had a 40 painting solo show in Alameda that went over quite well!

December 2015, A bad fall in the hallway of the college. Knee hit hard, and put me in pain for weeks. No more rushing, acting like the old normal. Tough way to end the year.

2016.. a year of troubles and increased diminished capacity. The year began with a great visit from Brian, then news that Bowie died shocked us all after such a great new album release. That night we saw Todd Rundgren at the Fox in Redwood City. A scorching show, encored with *Rebel Rebel*. Hardly a dry eye in the house.

Brian kindly brought me a walker with wheels and brakes. A deluxe model! on the airplane with him. So kind! I didn't feel I needed it at the time, but good to have just in case. After suffering a few falls, some in the home, I begin to use both a cane with a walking stick to help. Balance. The PT at Kaiser Oakland helps me figure this out. At least I could then still get myself off the floor.

April 6, 2016. The big bad fall backwards in the home. Hospitalized. Head hit counter. Blacked out, but still somehow managed to dial 911 in a semiconscious daze and get helped. I wake up in Highland hospital, with an iv attached. I only recall Sebs #, and he visits and takes me home several hours later, to find a huge pool of blood on the floor! Hard to imagine that much was from my head and survived. I came out lucky!

A major wake up call to slow down in the home with canes at all times. I start to use the walker that week, inside at night mainly.

Bri visits again, and helps make the apartment safer. We have a great time enjoying SF, dinner at TXR, and got my telescope on Mt Tam with the SFAA — Bri loved it!

Walking gets harder. Still using a cane, but no more 5 mile walks. 1/2 mile becomes a challenge. I continue to teach a class with my weirdening voice, taking BART in, but

needing the handicapped chairs. I no longer can stand on a moving vehicle. Regularly using my handicapped parking placard.

Spring 2016 is my last semester of onsite teaching. I continue to tutor in the summer, since the students can understand me in small groups. I love tutoring at the ARC. Great people!

June 2016, Old friend and neighbor Tom Crumley visits for a day! Unfortunately, while here I fall twice on the sidewalk! First near Ocean Beach while walking around the car, my attention was diverted by a lost smart phone I noticed on the sidewalk. Down I went, and hurt knee badly. Later the same day, walking to Zachs pizza, my foot snagged on an uneven sidewalk crack, while talking to Tom. I was weakened by the earlier fall, and got banged up much worse. Nicely, good folks helped me up and to the car. Tom bought first aid nearby. This was bad, and it clearly shocked Tom. He gave me a departing look as if he'd never see me again.

From now on, the double walking sticks will not do, and I need that walker Bri brought, which I always use now. Figured to a way to load in the car by tipping it in sideways, wheels out. A new reality. Good friend Louis visited and lined it up with light wire! A fun way to stay visible.

Had a great June visit from Tony of Mpls. We caught a great Justin Hayward show in Napa, and a terrific Phil Lesh day at TXR.

July 2016: Brian fundraiser ends, getting me 15k over a 1 year span! Perfectly timed, since this is the month Medicare and SSDI kick in! With working part time, its enough to get by..but I know my rent is a bit too high, and I do not want to endure another winter in this basement apartment in Oakland...but it is a nice large space.

I aim for Marin where I need to be, with the help of the *Marin Center for Independent Living*. Kelly is a friend of Robert at the drum shop who tips me off. The search begins!

September

Great visit from good old Mpls friend Jack for my birthday. It was the first fun birthday I've had in ages, with Todd Rundgren playing, Phil Lesh playing, and a dinner party at Terrapin Crossroads with a long table of friends! I billed it as my 93rd birthday!

Fall 2016, I am okay'd to teach online! This is great! The way to keep my career! I was mourning the loss of onsite teaching. My last semester tutoring, driving in to park within a few blocks away and hobble slowly through busy downtown San Francisco with

walker. I am through with the BART and elevators.

The MDA bring over a power chair for me! I test drive it, really smooth! ach..but..cannot fit in doorway, and no ramp. Drat! I could really use this. I no longer walk to BART and back, but drive only. Transportation gets rougher.

October, and another Brian visit! This time I treat him to Paul McCartney show in Sacramento! He pushed me in the transport wheel chair that Lee found for me. Great show!!

Moving slower, and I realize that a winter in Oakland hell is apparent. I ask Lee and Bruce to help build a quick railing along the sloped driveway. I cannot safely move on the slope even with walker. They build a great one, and added Christmas lights!

Dec. 22, 2016. Bad sidewalk fall on Piedmont avenue. I was looking ahead, not down, when the walker hit a snag and I tumbled sideways, landing me in great pain. 3 guys passing by generously help me back up. I hobble back home. The pain worsens the next day. Xmas eve and excruciating, I call out to any available friend to get me to urgent care. Badly, my Medicaid was mysteriously axed! So, no more Kaiser insurance! Super kind friend Molly was in town, and generously got me in to Sutter Health. The fall gave me sciatica, and the pain made me stay inside for 18 consecutive days. Misery. Lee helped the most stopping by daily, and I ordered groceries.

Winter 2017. Recovering slowly, I start to get out. Joni, Craig and Karen visit! So helpful and great. But Karen catches a killer bad cold that has been going around, and it rains the whole time.

I later catch the killer cold, and thought it would kill me. Winter is hell. Long, painful, lonely, worried, sick, wet and cold, with heating bill sky high. I now need warmth more than usual. Cannot wait 'til summer. I still make the best of it, and score a new class to teach online with the *Web and New Media* department!

Happy to be a weekly regular at Terrapin, which becomes my fave place to be. Phil's shows help to keep me vertical! Spring weather improves, and my mood and movement with the Sun! More outdoor shows!

And with help from Joni and great social workers at Kaiser, I get Medicaid back! I finally get a *Medical Guardian* lifeline to wear in case I fall. I end up needing it one evening when I lost balance and tumbled down on the street on the edge of the driveway. I push the button, get a call, they sent the local fire dept to pick me off the ground and

escort me inside. (They loved the art in my gallery apartment!) Fortunately only bruised this time. No pools of blood.

Spring 2017

Friend Jon — aka Mr Science, I've known from Cacophony — helps us get the big telescope to my old favorite local dark sky observing site at Lake Sonoma! It was perfect, we saw NGC 4565, the Markarian chain, and several other fantastic favorite sights of late spring that can only be seen outside of light pollution! A final farewell to those galaxies.

June. Some perspective at the King Crimson concert in Oakland. Good friend Rango drives me there, I get in to be set up in a handicapped area, and in one of those sections was a guy in a power chair who hardly had any body mass at all, with mutated limbs. Yet there he was controlling his hi-tech setup, able to enjoy the extraordinary performance. My abilities were like being Superman compared to him.

Still no apartment in Marin, but then the lottery date is announced as August 3rd! A couple months away, but I have high hopes! (Which failed)

So, in the past year and a half, I am weaker and slower in fine motor ability in the fingers, and walking. Speech is awful, but plateau'd somewhat.

I could still draw! But hard to hold a sketchbook up, and control is diminished, so I work with limitations. I can barely write or spell, but drawing figures come natural. I have not painted for a year, and not much astronomy either. No more pushups. And hard to hold my arms up for long.

Still, hanging in there, making the best of it against large odds. Going to Terrapin Crossroads for music and dinners have been very helpful. It centered and motivated me.

My jokes are getting a bit old that I am aspiring to be a brilliant baseball playing astrophysicist...the hard way!

For my rapidly advanced age of "Ninety-Seven", I explain the youthful appearance as being attributed to the portrait hidden in the pantry of not Dorian Gray, but a different DG!

"Hello sir, can I help you?"

"How about reducing the gravity of the Earth. I need to hover!"

Well I am like an alien astronaut now,...moving slow through an inhospitable environment for my spacesuit.

I am **The man who fell to Earth** now...literally!

July 2017: The loss of brother Brian, shocking us all, after he'd been doing so well after his lung transplant. He has been the greatest help to me and a close bro. We spoke weekly, and he was going to visit this month. Hard summer. Grief stricken. I wrote a list of memories of our times together. Threw a memorial dinner at Terrapin for him in early August, where 12 friends who knew Bri showed up, for a great time he would have appreciated. He is missed tremendously.

August 2017: Did not get that apartment in Corte Madera. The lottery was a long shot for such a desirable place.

Late August I fell in the apartment, injuring ribcage slowing me way down for a few weeks. No fun.

Warm **September** weather, and a big, fun birthday party at Terrapin made for a good month! I do love this time of the year. The TXR staff are so incredibly great and hugely appreciated! Going there helps immeasurably, where I've made several good friends.

I am down to one class for fall 2017 semester, since I lost my Medi-Cal benefits by working too much over the summer! Frustrating bureaucracy, in a complicated game. Still, I soldier on. Happy with what I have to be happy with.

Moving slowly and methodically to remain safe.

Jon helped me to my final star party on Mt Tam. Wonderful conditions! This was a private SFAA star party. I used to go for the public events more, but this was perfect.

Dec. 2017. Often a hard month. Getting colder. Still in the big but hard to heat apartment. I seemed to have plateau'd this year until now. Shakier, walking more timid. Harder to carry walker up and down the stairs. Finger grip weaker. And knee pain and back pain keeping me inside too much.

A few hard challenges...

Swallowing pills with water fails more frequently. Thick smoothies help.

Getting to a bathroom on time. I move so slow I need to plan my schedules around that. cannot be urgent. [later I gave up Riluzole, which contributed more problems than solutions] and I stopped taking Neudexta, as it messes with my bowels. So I laugh like a

lunatic..so what.

General weakened everything...but still can stand for a long time, but not walk well.

ALS is like I've heard, "*Death by a thousand paper cuts*" as abilities become continuously whittled down, bit by bit. I'm hanging in there, as one who has spent much energy doing difficult things, and up for challenges.

The best thing is that the city of Oakland finally painted the front curb blue! But its scarier walking down the bumpy driveway slope and loading the walker in the car without fear of falling. I need to move, asap...but where and how? Considering returning to Minneapolis but difficult to find a way. Attempting was made with help from Craig, but nothing reasonable found. Other harshness is I lost health care again, just like last Nov. 1st..????? Help may get it up and running again, but when? Ach. The lonely holidays. Hoping for a somehow better 2018. This has been an awful year, except for regularly going to Terrapin when I can! Brother Brian is particularly hugely missed.

2018

Many changes. Moved January to a much nicer apartment in San Rafael!!!! I had great help from family and friends with everything! boxing, wrapping art, and moving. I can barely handle just one box anymore. Needed to move after my worst winter ever. Need this warmer space with no stairs, elevator and view of Mt Tam! What I wished for and directly behind my friend Roberts store of vintage drums! Excellent score, with lease help from Craig and Karen!

But have been stuck inside all **February** with severe back pain in scapula area. I think due to pushing myself up out of bed with right arm, plus hunching over the walker to balance putting too much strain in that area. I'm changing positions, doing better finally. I did find out via x-rays that I have five broken ribs! And they are not healing fast.

Two falls in February happened. One at Terrapin on the sand. So I got new boots with fresh tread.

The other fall was at my car, trying to close the back flap, lost grip and was flung backwards. Not good. Help eventually arrived as I lay on the garage floor. My medical guardian button was too far out of range to work from there.

Good news is I can finally have the power wheelchair from the MDA! No stairs! No longer driving a car, to be safe. I've been confident driver well all along, but realize a bad surprise ability failure is not acceptable. Safety and wisdom first, even though it

depresses me to lose that flexible freedom. Plus I am more centrally located now for access to much with wheelchair and rides. I still plan to stand with the walker, especially at shows...but balance activities with wheelchair time. It'll take time to get used to. The other day I took it out for errands on 4th street, which felt great after being house bound for so long!

I gave my trusty Prius to sister Joni as a birthday present! My Seattle family, since they've been generous, and could use it. They flew down, had great visits, then they drove back.

Teaching two classes this semester, which is great! Now using word predictor software for easier typing. My fingers have definitely weakened. I do need extra help more often, so should try to have IHSS set up soon. I also have Kaiser back, paying in place of no medicaid, but important. A terrific OT has visited me with tips and equipment that helps, so that's good! Next I need PT, and return to my chiropractor!

And get back into drawing and dancing [only while holding a sturdy bench] at Terrapin! Those activities keep me stronger, happier and nimble!

Fall 2018

Summer was fairly even. Getting accustomed to the wheelchair and para-transit rides, I'd go to Terrapin solo by day, then get a transit ride back. I do better in summer weather. September was great, annual TXR birthday party was a blast! They made a custom birthday card, From Your Terrapin Family! Signed by staff, including Phil Lesh! Always nice to me. Amazing! Good friends rule! Soon after that I met Juanita at a Terrapin show. Super sweet and positively magnetic, who really stepped up to help me just over a year ahead. For now, we were enjoying Terrapin Crossroads shows of Phil and friends! Including a fine Leo Kottke performance that November in the Grate Room!

October had some scares. Fell a few times, for the first times since February. Home modifications help, and I've adapted. I also now have a speech generating computer, but it gets in the way so I've never taken it out.

I now don't even walk with the walker a few yards anymore. Not always, but a few times I had panic attacks when transferring chairs in the apartment, causing increased uncontrollable shaking, which is dangerous and unpredictable. I should walk more often, but only when someone is here.

The next steps are finding disabled friendly housing that is affordable. I am giving up on

the Bay Area. Too pricey with low availability, so am applying in Minnesota.

Meanwhile, to help afford my absurdly high cost of living, I started a gofundme campaign, whose generous donaters have helped quite a bit. As we've heard, "winter is coming", and I always do worse in the wintertime. As always, doing the best to hang in there.

2019. More demise, and that includes my drawing abilities,. Otherwise still regular at Terrapin Crossroads. This kept me engaged in life. Good friends visited from out of state ... Jamie and Althea again! Dhairyd! Grant! Nick! P! Robert! Tom! Joni!

May 2019. Todd Rundgren at the Palace of Fine Arts theater. Great! And I was paratransited in early, so I could roam the Marina solo for what became my final time. So I'm extra glad I did! A brisk sunny day, I zoomed along the path I used to charge up by bicycle for decades. Up to the hill above Fort Mason. It was marvelous. I later met friend Bruce at a pizzeria, and then to the show, Bruce treated. It was excellent! Seeing Todd concerts nearly 50 times!

Summer. Kaiser Marin secured this Tobii Dynavox eye tracking technology I'm using right now! I would bring to Terrapin in evenings. Everyone was astonished including Phil Lesh! Who was always nice to me, welcoming and supportive.

July 25th 2019

After returning back from a great fun Mekons show in the city, after returning to the elevator of my apartment building in San Rafael, I turned the wheelchair when my boot snagged against the wall and snap! Ankle broken! Arrrgh! The worst pain! The next day swelled worse. Went to ER, they gave me a big medical boot. I spent the next month and a few weeks convalescing. No fun.

September

Well enough by my annual Terrapin birthday party! Another great turnout, and local Melanie drove my telescope for a good final hour of sidewalk astronomy! Perfect! This was the last TXR party for me.

Autumn. The wildfire smoke reached near apocalyptic proportions. Indoors for two weeks. When cleared up, enjoyed the autumn leaves in the area, beautifully red for months. Juanita was back from Mexico where she stays for half the year. We enjoyed some final TXR gigs, and enjoy getting to the local cafes. She's a natural with helping out for disabled people like me. Super kind! She really helped with doctors appointments,

going with in the paratransit van from Terrapin. Helpful after my injury.

Winter slowed me down, especially at home doing common things, like getting out of bed, holding utensils to eat. I had been enjoying San Rafael by electric wheelchair, accustomed to the main drag of 4th Street, arizmendi bakery, the bank atm, Aroma café, the local bookstore, Albert park, and my now very familiar roll to Terrapin around one mile away! I know every bump, crack, and curbside of that route! All coming to a close as I get cold too easily and it's harder to bundle up solo.

2020

Juanita going with me to talk to the social security office about my ssdi being pulled yet again! A struggle to pay rent with my job limitations. I ended up canceling teaching to one class only. Craig and Karen helped me pay immeasurably. I can't possibly thank them enough!

Repeatedly injuring left ankle on a bolt protruding from my wheelchair, every time I swung my leg into bed. I didn't think that would turn into such a blatant pariah, and if I did have sense, would have had it altered or padded, but no, I let this repeat!

After the pandemic shut the whole world down, I had separate troubles brewing. The injury grew infected! Juanita who was a registered nurse, took action to have it checked out. I predict that she essentially saved my leg!

May 2020

Plus, taking showers and getting to bed required someone present in the apartment in case I get stuck. Bad news, as I started to use the emergency help button too much. Kaiser social workers considered me unfit to live alone. Ugh. The dreaded day arrives. However I found out about IHSS, (In House Support Services)

and I'm stopping here for now. It's so traumatic to revisit the years of losing independence and home. Like opening a wound. Speaking of wounds, the one on my ankle has been chronically open for 4 years now! Urgh.

If my reports on als helps somebody, I'll update this. For now I'm going to write about great times, like 1989.

But I'll leave you with these paragraphs, already written...

Summer 2020. Unfortunately symptoms worsened during that infamous pandemic year of 2020, my final semester teaching online for the Academy ended that June. After calling for emergency help a few too many times, 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. Being the pandemic limited most openings, especially in the over saturated Bay Area.

Fall 2020. 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 had excellent family help moving to Seattle. Yet it was a very traumatizing trip as we drove north I had a poignant moment. I bent my neck sideways to see Mt Tamalpais for a final time. Distorted out the edge of glasses reminded of the final scenes of the film "Seconds". A disturbing quality., a warped view.

Jumping to 2024. 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, April 2024

(Incomplete. continuing to add to this for years, now into 2024, and will add more later.)

I have a much shorter summary of this posted also.