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Proem

Welcome to the third in a series of conversations with Mighty Casey Quinlan of Healthcare is Hilarious fame. We both take the raw audio file and publish our production. Casey published her version last week entitled [Altered States](#). Mine is called Normal – a Dryer Setting. We used each other’s words with different perspectives on the same conversation. Fortunately, we’re both doing better than we were a few weeks ago. The prednisone erased my debilitating pain, I bought a new stand for my baritone sax, so I don’t carry the weight around my neck through my spine. I graduated from 5 minutes a session to 30 minutes at a time, even rehearsing with my band last night, and changed position with each tune. I’m walking better, though my altered state allows for less distance than before. I stopped taking a medication that dropped me into despondency. Life is good.

In addition to at the end, upfront, let me thank Joey van Leeuwen who creates the amazing music for my podcast, and Kayla Nelson, who serves as my web/social media coach and produces the video trailers for my podcast. You transform me good to great. Now for Casey and my musings.

Altered States. Normal is a Dryer Setting. 02:27

Health Hats: Both of us have been dealing with the up and down of altering states. I'm interested in how we adjust to these new realities.

Mighty Casey: New realities, new normal. But normal is a dryer setting.

Health Hats: I've been thinking a lot myself is, so I'm on the downside of steroids, which are the most wonderful drug in the world. And one of the worst.



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Mighty Casey: I have to say not a fan the one time that I was on dexamethasone during this period, over this year that, then having my adventure, I was like, if you ever tried to get me to take that again, I'm going to punch you in the face,

Health Hats: I feel that way until I hit a certain point. And it seems like the only thing.

Mighty Casey: The dexamethasone didn't do crap for the problem that it was supposed to. I felt speedy and tense and all this stuff that you get with steroids, and it didn't help. If it helped, I would have probably felt a little less face punchy about it. So, I'm like, do not ask me that again because no.

Health Hats: For me, each time I've taken steroids, whether it's for MS flares or this back stuff, it has always been magic in how fast and how well it worked.

Mighty Casey: When it works great. When something works, it's oh, it doesn't matter what anybody else thinks. I'm just going to keep doing this. Have they figured out what was exacerbating your back pain? Did they figure it out, or was it just, welcome to getting older or whatever?

Health Hats: I think the root cause, the most immediate reason, is swelling around spinal nerves. The question of how come now, is I believe, still being figured out. But I'm a guy that mainly focuses on function. What can I do? And what I can do has been changing. And I'm a born adapter.

Abilities. Disabilities. Adjusting and Adapting. 04:34

Mighty Casey: Based on that, I get exactly what you're talking about because having always been all my life and abled, shall we say right. As of today, I am now 69 and one day. So, I've been around. It was yesterday. It was great. Okay. I'm tired today, but it's a good tired anyway. I was always enabled, not as though I took that for granted or did not recognize the situation that other people, including peers and people that I worked with, were in with being not able to in some form function, et cetera. But now that I have crossed the Rubicon, the river, whatever. And I am currently in the zone where I am. I'm 69. So, I figure if you look at the span of history, human history, getting to 69 would have been considered miraculous a couple of hundred years ago. So yay, #winning, but because it's not as though I always entirely took my physical abilities for granted. I did get put on notice a bunch of times, even starting in my late twenties and early thirties with back injuries and, et cetera, stuff could go sideways on you quickly if you're not careful. And then, amusingly, at one point, I had a horseback riding accident that got me. It's a long story. The one trip before my reason for hospitalization, my one trip in an ambulance. But it turned out that the broken neck that the one place thought they were seeing because what they were seeing on an x-ray and the CT guy had gone home at a smaller hospital in Brooklyn. I had to wait hours. Anyway, so I got taken to another hospital in Brooklyn after hours in an ambulance. And then the neurosurgeon who finally showed up and read the report said, oh no, that's a healed break. And I'm like, okay. So, I broke my neck at some point and didn't know it. Cool. And it couldn't be the surfing accidents, the horseback riding, but there are so many times that I could have, but I'm glad it. Hey, lucky me. I didn't know. I broke my neck and didn't know. But anyway, now, I'm in this position of having to



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use aids to walk around, between a Rolling Walker and my cane. Then there was a period this year until after the hospitalization that I was just getting worse and worse than I could not even walk two steps. And, so it puts it, as a formerly abled who knows what situation I'm in. I haven't asked anybody to help me get a disabled or handicapped parking tag yet. I think that might be in my future, but I'll wait and see how good or bad things get, but at the same time, it does put me, despite my empathy for other people during my life - friends of mine who are in wheelchairs or, whatever a lot of different things. It's given me an extra layer of empathy for the situations they can find themselves in and just the algorithms you have to go through to figure out can I get in and out of that place once I get there and I get in. How do I get out? For example, yesterday there's a local restaurant that I adore. It's called perch, and the guy who is the owner has become a friend. He's one of the nicest human beings on the planet. So that's where I wanted to have my birthday dinner. But again, in their observing pandemic rules, everybody's very okay. Yeah, like sensible. So, I knew that I would feel comfortable and COVID safe while I was there, but I still see the restaurant's layout as well as I do. I called ahead of time to say, and I put it in my reservation that I'm immune-compromised now because of cancer treatment and need to focus on not sitting next to other people with them breathing on me. I called and talked through various seating options. And they ended up putting me in this space that they call the Lanai, which has room for a few tables. And there's also a passthrough for their covered patio area outside. And there's, there's inside, there's a covered patio, and then there's this little Lanai thing that's attached to the inside part of the restaurant. Based on where their restrooms are. I have no. You never have any idea. Am I going to need to go to the bathroom while I'm there? I don't know, but maybe I will. And the thing that I didn't want to do is go from the covered patio back out to the sidewalk and on my cane and then in the front door and then to the back of the restaurant and then knowing where the Lanai was in the layout of the restaurant if the bathrooms are just right over there. Yeah, just out and around. No big deal.

Planning to swim, eat out, live 08:46

Because when I leave the house, I'm trying, I want to get back in the pool in about a week. I'm working hard on getting up, getting my sort of comfort level, distance level, whatever, with my cane as built up as possible so that I feel safe with this idea of going in and out of the gym because I don't want to have to take my Rolling Walker and, work that in and out, whatever that sounds more exhausting than just taking my cane. So that's the plan, but so I did it. The parking for the place, it's like you go and I had to walk around it, but that's fine. It's good practice working my way to the gym. But it was like the algorithm that you have to do in your head. And then the pre-planning, it's okay how am I going to maneuver around in this place? And like what's my access point and how do I get from point A to point B and whatever. And I managed to get in and get out, even with martinis, wine, and rum as an after-dinner drink in the mix. I made it back to the car. My sister drove home. I drove there, and my sister drove home. She doesn't drink. No, I was covered in all directions. Planning, it's all in the planning, but that's the thing. People who do not have to concern themselves with any kind of physical incapability or, whatever is, it's just it's not something that they have to think about. And having been in that crowd for 60 odd years, it's just, even though I had a lot of empathy and understanding and would when I was making plans with disabled friends would make sure that I thought through, like, where am I asking them to go. What am I asking them to do? And making sure that I hadn't done something stupid. But at



the same time, it's just. You don't realize how much the world is set up for people who can leap tall buildings at single bounds. And how much of the world is not set up for anybody who can't do that.

Oh, that old heavy horn 11:33

Health Hats: Yes. Yes. I think there's also for me. It's been on a couple of levels. The main one is playing my horn. I can play 10 minutes and, 10 minutes is a tune 10 minutes is not sufficient. And I'm waiting on an assistive device. Hopefully, that's going to help me. But it's interesting, thinking about okay. Maybe I should start playing the kazoo,

Mighty Casey: Which horn is that?

Health Hats: A baritone saxophone. It's like a 25 pound (really 12 pounds, I exaggerate). That's good. That's a good size. It's a big horn. That's a big old horn. Yeah. And I love it. And I have played clarinet in the past, and I have played an Alto sax in the past, but I don't want to. And there's like figuring out that then it's the, I used to be able to go with two canes on a good day. I could walk three-quarters of a mile into town, rest for half an hour to an hour and then walk home. And now I'm fortunate to go six blocks. And thinking about, okay, is this my new reality? And okay, so what does that mean? I believe that part of it is as you're describing, is the logistical practical. Okay. These are the capabilities today. What does that mean in terms of going to the bathroom wherever you are, right. Or getting in the door or I, or whatever, but then I'm also finding it's the oh my God, this is the new me do I like this? It's I am this is oh man, this is the new me, but this, it's there's that piece.

#PatientHackers. @PatientHackers 13:25

Mighty Casey: It's a challenge to your ability to adapt, certainly. Going through this, like a version or, as a small slice of it, myself currently with the mobility issues presented my bone Mets, settled into my hip, pelvis, and lower spine. It just it's been an exciting journey again, the empathy piece. Not as though I was, I considered myself the most empathetic person on the planet, but I realized that even I, who thought I was doing okay, fell short in some things that want assumes about stuff, but it's, certainly put it on my mind now. And if I do, I don't think it's going to happen, but if I fully regain total mobility, I will be grateful for that. But in the meanwhile, in my current situation, whatever I can do, I will try to do, and whatever I can't do, I will figure, try to figure out a hack. And I don't know if you've seen online around Defcon and the biohacking village one, the patient communities involved in the Defcon biohacking village have come up with a new hack. We are calling ourselves patient hackers. So #patienthackers. It doesn't have anything to do with code.

Health Hats: I get it. I get it

Defcon 14:41

I'm having difficulty describing DEFCON to the uninitiated (like me). Wikipedia says DEFCON is one of the world's largest and most notable hacker conventions, held annually in Las Vegas, Nevada. The first



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DEFCON took place in June 1993, and today many attendees at DEFCON include computer security professionals, journalists, lawyers, federal government employees, security researchers, students, and hackers with a general interest in software, computer architecture, hardware modification, conference badges, and anything else that can be "hacked." The event consists of several tracks of speakers about computer- and hacking-related subjects and cyber-security challenges and competitions (known as hacking wargames). Contests held during the event are incredibly varied and can range from creating the longest Wi-Fi connection (aircrack-ng) to finding the most effective way to cool a beer in the Nevada heat.

Mighty Casey: Because people who confront the medical-industrial complex and have needs beyond, *yeah, okay, you're fine, see you again next year.* People who have healthcare needs beyond the *I don't need that. I'm okay.* You have to figure out how to work the system – hacking. So, you get what you need or your family gets, if you're a family, caregiver, et cetera, we're all hacking this all the time. And I think that it does a disservice to people who fix broken problems, broken issues, things that aren't working for them or for their communities. We're all hackers in that sense, it doesn't really have anything to do with code.

Health Hats: That's a really good frame. I liked that.

Mighty Casey: [Andrea Downing the founder of the Light Collective](#) was the one who first really put it online, put it up on the walls of the internet. She gave a talk yesterday at Defcon in the Biohacking Village about how patient hackers are, how a lot of the healthcare system could get fixed if they start listening to us.

Now a word from our sponsor, Abridge. Use Abridge during your visit with your primary care, specialist, or any clinician. Put the app on the table or desk, push the big pink button, and record the conversation. Read the transcript or listen to clips when you get home. Check out the app at abridge.com or download it on the Apple App Store or Google Play Store. Record your health care conversations.

[Help me hack it, please 18:02](#)

Health Hats: One of the hacks is asking for help. I find people are more than willing to help. I am blessed that I do not have inhibition to asking for help. Some people do, but that is not a burden I have. I feel like people can say no. That is surprisingly rich. On the other hand, on the other hand...

Mighty Casey: It's frustrating as hell.

Health Hats: Yeah. And I don't know. I hate to keep doing it.



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Mighty Casey: I feel ya. I have stepped across into a new land myself and asking for help or needing some assistance or whatever. It's been a journey. It's been an interesting journey. You've been on it a lot longer than I have. I joined the club toward the end of last year, at the beginning of this year. But this is Terra Nova for me, and you've been doing it a much longer. I get it because if you look at the world as it, tries to present itself to humans as our culture society, whatever tries to present itself, everybody's supposed to be able to do handsprings and, do all the things and enjoy their lives fully, et cetera. And yes, we are, but it's, that what we see presented. Yeah. Normal life again, normal is a dryer setting, but what is presented as normal human life is pretty much 99.9% abled world. And then there's this little slice that occasionally, you'll see somebody in a wheelchair or with prosthesis or whatever or blind or now with the Paralympics starting next week, we get a little bit more. But still, it's just the abled world presents itself as the normal. So, people who don't think about these issues, are Hey, when confronted with somebody who can't just do it *thank you, Nike*, whatever. And if you ask for help and you said, you've said you are good at that. I will ask for help if I need it. That's also a journey because for, as someone who broke barriers as a woman and as an engineer in broadcasting, back in the late seventies, early eighties, asking for help is something that the time was not in my programming. I, they, I had to erase that part of the code. I will say there were a few people. But asking for help I've certainly gotten better at it. And women ask other women for help without any problem. I know that men aren't coded for that culturally, as much as, women where we're taught from early childhood, that other girls will probably be more helpful to us than anyone else, other girls and women. And ask for help in that zone. But with guys, I think culturally we've really screwed you fellas. Particularly in the west at least. And most cultures that I could think of that I know of is that men are supposed to be the ones in charge. We don't need any goddamn help and we're going to do it all. We're going to know. Freedom!@. I'm like, wait a minute. What if you're actually a human being? I don't know a single human being they can't get through well, other than Ted Kaczynski, we all see how that turned out, but humans need other humans, we need help from other people to do anything really, pretty much. Not recognizing that is, I think one of the things standing in the way of human progress.

Health Hats: Interesting.

Mighty Casey: But you learn about that mindset. I think a little bit more when you find your own place in the world challenged by something. It could be anything from economic circumstances to physical disabilities, to access to education. All of the possible pieces and parts and intersections of human life, if one piece is missing you have to figure out the hack to figuring out, to get that part of the puzzle on your board. And it's almost impossible to do it by yourself. You will have to find somebody to help you hack it. And sometimes people come up with stuff on their own. Absolutely. But then you must sell the idea to somebody else. Cause if it's just you, that's fine. And you solve your problem, but did that help anybody else? You don't know until you go out there and offer it up and then you've helped someone else.

[C U Soon. Navigating in person during Covid 22:31](#)

Health Hats: So, I'm thinking we might see each other next week.



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Mighty Casey: I am thinking that's a mortal lock. I am tracking the infection rates both locally and up there. As far as I know, the conference is still on as of yesterday and I'm planning this week on pulling the trigger on getting my ticket. I've already booked a hotel. I'm really looking forward to being with other people. Hopefully my neutrophils, my white blood cells will bounce back by then. Stay tuned for updates. So I may have to be, like the high from, elbow thing. I will confess that last night while I was at the restaurant where I had dinner. The guy who's, the owner, chef, who's a friend. I hugged him. He was wearing a mask. I hugged him because he deserves hugs. And I just, it's one of those things where, you know, I just, I have to be careful. Oh. And then there was that day long con I'm gonna go to here locally in Richmond. The local tech council was going to have their first live event since the pandemic, which was the last event that I went to back in March last year. They were planning this Thursday on having their return to live events, but they've changed because Virginia, particularly this area is okay high risk of transmission. Up in Middlesex County, which is where Boston is. And that's where this conference is I can't remember, which is high, the higher high substantial one or the other, but I'm just keeping an eye on it. Yeah. I'm just going to mask up, take all the Purell, and just, try not to, I'm going to stay masked unless I'm putting food or drink to my pie hole. Done.

Health Hats: It's good to talk to you. And I look forward to seeing you.

F Cancer, I Ain't Done Yet 24:11

Mighty Casey: I look forward to seeing you too. Like I said, it's pretty much a mortal lock unless they cancel the conference. We're going to observe proper protocols, but we will still love the hell out of each other however. There you go. Thank you. Thank you, dear. It's just the things I've learned in the journey this year have been, it's a never-ending journey, this learning, as I was getting ready to depart from my birthday dinner is cancer can't kill me yet. I have too many problems to hack fix in healthcare. So, fuck cancer. I ain't done. I ain't quitting until I'm dead. And then I want you all to carry me off the battlefield on my shield and then keep fighting because that's the only way we're going to hack this universe into a more human-friendly place.

Health Hats: Thanks, honey.

Mighty Casey: I love you, man. I'm going to say I love you. Take care. All right, sweetie. Bye. Bye.

Reflection 25:09

My brain ties into knots when I hear people who expound on the impact of COVID say, what will the new normal mean for you? I think, what old normal do we leave behind? Whose normal? Isn't every day a new normal? I go up and down, back and forth? Normal, normal, normal. Normal is a dryer setting. A new normal feels fleeting, seeing shapes in the clouds. Normal, a frame without value. Pining for some vague selective old normal does me no good as a person with a progressive condition. Instead, I strive to understand and accept what is and then figure out my path to peak performance, best health. It's a superpower.



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I just love Casey. Can you tell? Dryer settings, patient hacking – pithy turns of phrase to reveal the essence. Casey, the outrageous revolutionary overlaying Danny plodding with one foot in front of the other. Both are strategic, practical, and charismatic. Look out, world. Thanks for joining us. Onward.



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