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Proem

My dear friend, Mighty Casey Quinlan, of *Healthcare Is Hilarious* fame, continues to cope with her breast cancer #MetsParty. We co-produce an episode when Casey doesn't feel well, and her audience clamors for news and wit. I recorded conversations that we both could use for our podcasts twice before. Let's jump right into our chat.

Podcast intro 00:29

Welcome to health hats, the podcast I'm Danny van Leeuwen a two-legged cisgender old white man of privilege who knows a little bit about a lot of healthcare and a lot of our very little. We will listen and learn about what it takes to adjust to life's realities in the awesome circus of healthcare. Let's make some sense of all of this.

What's new for Health Hats? 01:09

**Mighty Casey:** Hello, dear. How are you? What's new?

**Health Hats:** What's new? I'm working on a series about young adults with mental illness.

**Mighty Casey:** OK, That's useful.



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**Health Hats:** Yeah, it's been fascinating. Pulling it together and meeting people and thinking about its scope. And finding people with lived experience to share their stories so it's rooted in reality.

**Mighty Casey:** Yeah, exactly. What types of diagnoses are you finding most common?

**Health Hats:** I don't know what's most common, but it seems like it's going in two directions. One is with people with lived experience with some severe psychoses. And I found this organization called [Students with Psychosis](#). It's an international organization, and then I've been talking to primary care docs. I'm trying to line up an ED doc, and I've got some community organizations that coordinate services for teens. And then I got one of these referrals from somebody I respect. You'd be interested in this guy. And it was like cardiac rehab, and I wasn't that interested. The person who referred me, I do respect, and she's been very helpful. So, I said, oh, I should definitely talk to this guy. And I told him I wasn't that interested in that. But what I've been interested in is this young adult thing. And he said he's a firefighter and started a Yoga Five-O program. He invites first responders and teens to do yoga together. And I said, now that's interesting.

**Mighty Casey:** That's interesting indeed.

Casey's health-kidney function 03:26

**Health Hats:** So, tell me, tell us about your health.

**Mighty Casey:** We'll just say it's not great. I went through, let's see, at the beginning of this year, things looked OK other than I did get a mild case of Omicron, a breakthrough. I guess it was like the first week of January. But after that, everything seemed to be just bumping along. But then, in April and May, my kidney function started to look funky, right? Technical term. And June, I was in the way of needing to see a nephrologist, and there was some deep concern about kidney failure. And the last thing I want to deal with right now is dialysis. So, I was working on, OK, how do we get past this? And they also, at the same time, were strongly suspecting that it was because of the treatment I was on. OK. The oral medication I was on for my cancer was part of the problem because there were a lot of other issues around anemia and calcium levels. And things just kept going further and further down into the shoot. And then that led to me being hospitalized twice, once in August and once in September. And they had taken me off the medication I was on, the breast cancer medication I stopped taking. I want to say it was in June. But it took a while. My kidneys are OK. They're not great but no longer in kidney failure zone. And I mean, all the blood numbers related to kidneys are OK. My calcium level has gone back into the normal zone. Occasionally they have to hit me with a drug called Zometa. That is what that does. It reduces calcium blood calcium levels. And they haven't had to hit me with that for, I guess, like a month or so now. So that's good.

Casey's health - chemo and radiation 06:00

**Mighty Casey:** I'm on traditional chemo versus the oral medication I had been on. I'm on a class of drugs called Taxanes. As we're sitting here looking at each other, people will be listening to this, but yes, all my



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hair fell out, but that's fine. And I'm not going to cry over spilled hair. Why worry about it? Other things are more important, like getting this cancer under control. I just had a CT scan yesterday. A progression scan and things at a stasis point. There's a spot on my liver that's been there for a little while. I did end up with a broken rib. I was pretty sure it was a broken rib. And that was a pathologic fracture from just the way cancer is in my bones and my spine. And I had broken ribs, visible, healed broken ribs visible on an MRI last year. When I felt like I had a broken rib, I was pretty sure it was. And it was. The pain has passed off now, blessedly, because that was pretty awful.

**Health Hats:** I bet.

**Mighty Casey:** Yeah, but the pain only lasted for, I guess, like a week or so, maybe ten days. It wasn't that bad. But they're talking about maybe doing another round of radiation in that area, just so we'll see. But I'm chemo-brained badly at this point. I can still work on audio and video editing and projects that I do the stuff that I do for medical journals and societies but through a major publishing house. But I can't write. I can't write to explain right now. I had to turn down a writing project worth a few thousand dollars this month just because I couldn't. I'm just not in the zone where I can write like that. And they're infusing me every three weeks. I go in for another infusion next Thursday. And the cadence seems to be that the first week to 10 days is the worst of the chemo brain. Then I start feeling a little better or a little more with it, but I'm still not hundred percent. I'd say that at my best, I'm probably running about 80 or 85% at this point. But I'm down to about 40 to 50 seven to 10 days after receiving an infusion. But I have no idea how long how many of these they're planning on hitting me with. My very unscientific wild-ass guess is somewhere around 12 to 18 of these, which puts me well into next year. Wow. I think we'll see. It's the one question I keep forgetting to ask, and I will remember to ask next week when I have my appointment with my oncologist. How many of these do you see us doing- every three weeks for 12 to 18 weeks? That's six months and or close to it. So that takes me well into next year. And right now, I'm concentrating on the small stuff. I still want to get back in the pool.

**Health Hats:** When was the last time you swam?

**Mighty Casey:** I'm, hoping. I'm aiming to get back in the pool sometime in November. OK. And November, we'll see. Time will tell. Yeah.

Casey's spiritual health 09:30

**Health Hats:** So, how's your spiritual health?

**Mighty Casey:** I'm doing OK. Spiritually I am seeing or talking to a palliative care group. And I'm OK. I can't say that I don't there are good days and bad days. I'm OK. I don't know where we're headed with this short-term or long-term. But I'm just waiting for signals, and there may not be, and who knows? Who knows. But again, I'm the progression scan didn't give us anything to hang our hat on. Nothing has changed a lot. Yes, they confirmed that I did have a broken rib. There's a little bit of ground glass in my lungs. They think maybe that's a leftover from the covid. Although my covid infection was so minimal



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that it doesn't seem to be, I don't know what's happening. We'll see where we end up. OK. But I'm just every day I wake up, and it's a day, and I live through it, and then we do it again the next day. Yeah. And if that keeps happening, I'll keep pressing forward.

A word from our sponsor, Abridge 10:59

Now a word about our sponsor, [ABridge](#). Record, your healthcare conversations with doctors and other clinicians with Abridge. Push the big pink button and record. Read the transcript or listen to clips when you get home. Check out the app at [ABridge.com](#). A B R I D G E.com or download it on the Apple app store or Google play store. Let me know how it went.

Recognizing success in advocacy 11:40

**Health Hats:** Can I ask you some not health-related questions?

**Mighty Casey:** Sure. OK.

**Health Hats:** So, when you look back on your career as an activist, how do you recognize success in your work?

**Mighty Casey:** Because what we're all trying to do are such a huge heavy lift and giant pivot. For a long-established, hierarchical setup, process, industry, or whatever you want to call healthcare. I don't know. Occasionally, I will hear something that gives me a sense of some potential change that has happened. But pretty much everything is going to be recognizable more in a look back than it's going to be anything that you can see happening, like in real-time, around you. And I think my measure of success I don't know that I have one. OK. I get up every day and go and do what I do. And if somebody, if I hear somebody saying something that I know I've been saying for a decade, but I never heard them, or that group says it before. Yeah. That's progress. That's progress, and that's progress. Great. And we managed to create a little bit of something there. We'll see. But

System change 13:24

**Health Hats:** I went to the Healthy Voices conference. And I asked people about how they recognize success. And one of the things that I found interesting about that group, I interviewed 26 of the 95 people there. And, they all said something to the effect of if I can make an impact on one life, that's worth it. And I thought that was great. And I also thought they weren't thinking about systems. And I know that one of the things about you and your work is that you're almost always thinking about systems. That is why I wanted to understand how it's so hard to see system change.

**Mighty Casey:** Again, it's just watching some of the larger sorts of institutional players in the space, and that's everything from like healthcare providers to policy tanks, to think tanks to whatever. At least the



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more progressive thinkers among those groups seem to have started to wake up to the idea that there might be Kool-Aid to drink. I don't know if they have drunk the Kool-Aid yet. Some are at least looking for a pitcher to mix some Kool-Aid. And we'll see. But then we'll do a test, or we'll do a pilot. The thing that I see too many sorts of industrial side players trapped in, though, is that death by a thousand pilots. They do a thousand pilots. Yeah. And, but they never actually do an entire system through their entire system. Yeah. They don't flush through the whole thing and change their processes enough to make it truly patient-centered. Yeah. Patient-focused. Even patient-led, in some cases, they could do with some patient leadership. And that's why organizations like PCORI, the Patient-Centered Outcomes Research Institute, and other international groups are one of the reasons they came into existence to at least try to push some of that through. But again, we're dealing with this vast hierarchical structure built over millennia. And not very scientifically based, let's say, 2000 years ago. We've gotten a little better in the last couple of hundred years, but we're still tripping over ourselves as a species discovering things and figuring out maybe that idea about the leeches was not good. There's still some leech stuff that's left lying around. Why do we keep doing something if it's meaningless? Or if it's just because it's the way we've always done things. So that's why we're doing it this way. I mean, looking at processes and systems and saying, why do we do it this way? Is there perhaps another approach we can take? That would be safer, faster more effective. Pick your descriptor. But it was just trying to think of new pathways and ideas beyond the scientific experiment.

Quantitative versus qualitative 17:13

**Mighty Casey:** The other battle that drives me crazy is this whole qual versus quant. Or, you know, the qualitative versus quantitative. Everybody wants their numbers, and they want their little data sets, and they want them, and they want it very scientifically. We titrated this, and it was a chemical formula, and then we did a, we did algorithms, and it was all about the data and the numbers and the statistics. And that's that when it's quantitative, then we know it's real. But if it's qualitative, that's soft skills, and that's just people talking to each other, and we don't see any science in that. What the hell? Wait a minute, no, that's not right. But we're still in that zone.

Advice, oh wise woman? 17:59

**Health Hats:** If you think about our mutual audiences, what advice do you have for us in these trying times?

**Mighty Casey:** About anything or just everything?

**Health Hats:** In terms of our work, do you think, Oh, this works? Yeah. I found this over and over, this works, and I'll prime you because I know one of the things you'll say is to build relationships across bridges. It is Something you've said since the moment I met you.

**Mighty Casey:** Yeah. You have to bust the silos. You have to break down those communication channels silos as much as you need to break down the silos between data exchange, et cetera.



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**Health Hats:** What else?

**Mighty Casey:** I don't know. We've got globally and then our own in the US of A thing. There's a vast species-wide challenge. We've got so many things confronting us right now—everything from the fact that we've managed to screw the climate almost beyond recognition. Also, the rights of individuals as citizens seem to have become less important than the rights of some rich people who get to buy governments and put their little puppets in there and have it all be the entire system of everything set up to reward them: these very, a small percentage of humanity. And the rest of us can all go between the United States and then the rest of the quote-unquote developed world or the world that observes democracy as an actual process. Although that's an open question right now, given the way that democracies, in many ways, are behaving. You look at the UK and the US. Between us, we're such a hot mess. It's hard to wrap your head around how bad things are. Suppose you sit and think about the macro picture too much, though. You can end up stuck because there's just stuck. Yes. So much that's wrong that we thought we were making progress, but instead of the two steps up and one step back, it's like we took two steps up, and now we're rolling back three centuries. It's, wait a minute, are we going back to the feudal state now, and are we all going to just basically be sitting at the foot of the castle walls waiting for the nobles to throw some scraps out so that we can eat this week? Yeah. That's where we're at.

**Health Hats:** Thank you. This is lovely. Thanks for doing this with me.

Reflection 21:28

Bald is beautiful and shows on the outside. Brain fog seems to be something to feel on the inside. On the outside, today, Casey sounds lucid and humorous, can spin a yarn, and offer us some wisdom. On the other hand, I get feedback from my family that I don't make sense to them when I feel together on the inside. Nevertheless, I'll pray for Casey and her sister. Sounds rough.

I spoke a bit about the new series I'm working on: Young Adults with Mental Illness. I've lined up several recent young adults with lived experience, family, a teacher, family practice, pediatric and emergency physicians, adolescent psych inpatient administrator, community services providers, researchers, and more. Our mental health systems appear more fragmented and understaffed than ever. COVID lifted the rock off an already inadequate, unsatisfying, and desperate system. I hope to focus partially on prevention and success, as the unmitigated disaster unfolds before us. These are our kids, our future. I've scheduled interviews over the next month. I don't know how they'll fit together or when I'll begin. Hold on. It's coming. If you have something to contribute, get in touch. Thanks.

Podcast Outro 23:09

I host write, edit, engineer, and produce Health Hats, the Podcast. Kayla Nelson provides website and social media consultation and creates video trailers. Joey van Leeuwen supplies musical support, especially for the podcast intro and out. I play bari sax on some episodes alone or with the Lechuga Fresca Latin Band. I'm grateful to you who have the most critical roles as listeners, readers, and watchers. See the show notes, previous podcasts, and other resources through my website,



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