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Proem

Let me introduce my dear friend, Casey Quinlan. Last week, when I said that I’m a lousy revolutionary, I thought about Casey, a much better revolutionary. Casey uses the handle, Mighty Casey, and publishes the podcast, [Healthcare is Hilarious](https://www.health-hats.com). I sponsor Casey’s podcast through Patreon. While our approach to healthcare activism varies considerably, Casey is one of a handful of activists I consult when I find myself in a hole I can’t get out of. She’s a clear thinking, irreverent, expert in change management. Most people I chat with on my podcast have the most serious chapters in their health adventure behind them. Not so Casey. She’s in the eye of a metastatic storm and can’t find the energy to keep her storm chasers in the loop. I offered to record a conversation she could fling into her podcast. She agreed to let me share it



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with you here. Doing something with two birds and a stone. To listen to the episode in the raw, go to Casey's podcast on your favorite player, Healthcare is Hilarious.

Greetings and salutations from the confines of the pipe 02:07

Mighty Casey: So greetings and salutations.

Health Hats: Greetings. I love seeing you

Mighty Casey: It's not bad to be seen. I will say that I'm not feeling like myself lately. It's not that I've been hiding out, but I just haven't really had the I dunno, the bandwidth, the emotional pick one, whatever, to really be as much of a public persona as I typically am. And also because I have very little understanding of what the fuck is even going on. I know what's going on, but what the outcome or the impact of what I'm doing is, whether or not that's having any impact on my overall survival time. No one knows. And we won't know for a while. I feel like I'm being shoved through a pipe and I'm just being shoved through a pipe and here I am in the pipe,

Health Hats: So say more about what does that mean, being shoved up a pipe?

Mighty Casey: For those who maybe coming to this cold, since August of last year, I have been chasing what appeared to be a back problem that just was bedeviling me. It didn't seem to be giving into physical therapy or exercise or any of the usual stuff. As a result of that, nothing worked and everything made it worse. The stuff that had typically fixed it previously only made it worse - swimming, et cetera. That was disturbing. Then I guess in early March, an MRI revealed that there was some metastatic mess going on in my lumbar spine. And so it was like, oh really? And it turns out I have a recurrence of breast cancer. And so here I am with the metastatic cancer diagnosis and I still have terrible mobility issues. I'm still not fixed on the spinal side. There's some argument on both, from my perspective, and also from the professional perspective about how much of this is due to cancer process and how much of it is a separate issue that has to do with the fact that my spine is a mess. I think it's a little bit of both, but now, I think it's probably more that my spine is a mess, then that it's a particular metastatic process. But I do know that there was stuff, there was mets (metastasis) and cancer in my pelvis area and into my my hip. I had a hip surgery, not a replacement or anything, but just they put a rod in to prevent what's called pathologic fracture, which sounds really awful. I would like to avoid that. So I did. And it's this spontaneous fracture of a hip because of weakness of bone because of metastatic cancer in the bone. Anyway, so I managed to, I hope, avoid that, but yeah, it didn't improve my mobility to have that done. And my orthopedic surgeon is as disappointed as I am that, that is the case. But I had radiation, which supposedly over time is or, with the blessing, is supposed to perhaps address some of this issue with, the bone and the, the spine, but that hasn't happened yet.

Mobility, a burr in her saddle 05:22

Mighty Casey: I'm still, dragging myself around. It's difficult to get up and walk.

Health Hats: Is that because of the pain?



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Mighty Casey: It's because, because the pain from putting weight on the right side of my hip, or just, like standing on my right leg. It just, walking is just it's even with the walker. It's a hot mess. Yeah. And mostly I can't, and I can struggle from point A to point B. And getting in and out of the house is really hilarious.

Health Hats: Because you have steps and stuff like that?

Mighty Casey: Yeah. There's steps out front and yeah, I can get up and down them, but it's not something I want to do more than once a day.

Health Hats: How is it sitting?

Mighty Casey: I have to move around. I've had some impact of digestive problems. We'll leave it there. I'm on Oxy for pain, sometimes that can plug a person up that has not happened because of other things going on. But yeah, so I'm having the opposite problem. And so as a result I've got other things going on that are unpleasant. Sitting isn't terrible, but I do need to move around.

Health Hats: I'm thinking about, okay. So the ways to move around are to be carried, to be in a chair to walk. And so it sounds to me, like you're saying that any of that in large doses is problematic.

Mighty Casey: Oh yeah. Like I said, getting in and out of the house is an adventure. I do it. But the stairs out front are a thing. Again, it's, it's not something I want to do more than once a day. Usually I try to limit out of the house medical appointments to, either once a day or put them in a clump and then, leave the house and go and do, be hither and yon and then, go out once and come back once. And that's it. And yeah, right now there's not a lot going on. I had radiation treatment for a couple of weeks and that was a daily deal.

Health Hats: Okay. So it was like trying to get outside every day and navigate the steps and all that.

Immobility and living alone mix like thinking and drinking 07:33

Mighty Casey: Correct. So that went on for a couple of weeks and ended a week ago today. And that wasn't terrible. My sister's here, which has been an absolute blessing because, otherwise I'd be screwed.

Health Hats: Cause you live by yourself.

Mighty Casey: Yeah, I do live in, and right now I am not really able to live alone just because of the mobility stuff. Yeah. Yesterday I went back to the spinal specialist that I had been planning on working with until we got the metastatic cancer diagnosis surprise back in March. And so I reopened that conversation yesterday. And it's okay, now that we've gone down the cancer rabbit hole and we're doing that. And that's ongoing. How about we readdress the idea that Casey might be able to get up and fucking walk again at some point, let's not ignore that because, until earlier this year, I was able to get up and walk without having too much trouble and sure. Okay. I have stage four cancer that has impacted my skeleton to some degree. But okay. How much of that is fixable and how much of it is not? And that's the answer that I'm speaking right now. And as far as I can tell I think that this might be



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addressable, but again, I don't know how. So that's what you know, but anyway, so you know, this guy's a spinal specialist, conservative treatment, not, one of those immediate goals. And we'll just, we'll see what he has to say. He's sending me for yet another MRI. Not my favorite thing. It's not that I'm super claustrophobic, but I've had enough MRIs lately that it's I can live without this,

Health Hats: it's so uncomfortable laying and plus, you smashed in a tube being pushed through a pipe.

Mighty Casey: Yeah. And it's okay, great. I probably will ask them for Ativan just because, and they haven't scheduled that yet, so that'll be it's, if the Jurassic MRI at some point in the not too distant future, Stay tuned for updates.

Bemused, bewildered, be fuddled, be bored, be tired 09:49

Health Hats: Are you like pissed off?

Mighty Casey: I wouldn't say I'm pissed off I'm bemused. Not pleased. We'll just say that Casey is not pleased at the idea of a stage four cancer diagnosis. Again, because I know so many people who have been on the receiving end of those various types it's it's not as though I feel as though I'm the only schmuck in the universe that's gotten stuck with this. Far from it. And also not that it's like I'm supposed to go home and die now. No, death is inevitable for all of us and who knows I could be seeing, like sort of the end of my line as it were, but not as though that's happening this week or even this month, I'm not feeling as though I'm about to shuffle off. But who knows, because death is by the way, an inevitable outcome for all of us, no one gets out of here alive in case you missed the memo. It's still only a theory. It's not something that I figure is happening this week or this month, or possibly even this year. But the fact that I'm now at the point of eyeballing my mortality pretty squarely. It's oh, hi, how are you doing? Yeah. How are you? Yeah. Guess what? Hey there.

Health Hats: Okay. So are you are you bored? Like you're a such an active person.

Mighty Casey: I will say that not being able to do much is not my usual. This is wearing me out that I'm tired. Some of that is medication related to the big fancy medication that I'm on. The one that's \$14,000 a month, if I paid for it. hello, thank you. American pharma. But the drug that I'm on, which is one of the ones that they advertise like crazy on TV. And then it's okay, it's interesting that stage four metastatic cancer treatments are like worthy of television ads on primetime television is like really? Anyway, I've been having a fist fight with the pharma folks over TV ads for over a decade. It's like you guys, the fuck you doing? But anyway they're spending an awful lot of money that to me seems well, we could, you keep talking about how R & D is that's what your biggest bottom line is, but then meanwhile you're spending billions on television ads to fuck. Anyway back to our show already in progress. But anyway, so this big drug that I'm on one of the but, one of the main side effects is fatigue. And the other thing is that my blood numbers have been terrible.



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Be cooked, be home 12:18

And some of that is because I don't really have an appetite. It's not that I'm not eating at all, but it's like, there's not a lot that really appeals to me. I am using a lot of like Meals. When I say Meals, like Door Dash, that kind of GrubHub, et cetera. And it's okay what appeals to me right now? And if somebody wanted to cook me something and bring it, it would be great. My brother was here for a week and he just went back home yesterday and he and I are both into cooking and he made some things that were, there was a vegetable cookbook by Eric Ripert from Le Bernadin. He brought this book and made some things from it. It was good, but I haven't been able to get into the kitchen to cook.

Health Hats: You've got to stand there.

Mighty Casey: Getting in and out of the kitchen is also fun just because of the way that my place is constructed and I can get in and out it's not, out of the question, but it's still, it's I have to get in there and then, go in there with the walker and the walker has a seat and, so I can sit, but then, the counters are up here and yeah. Not as though that's impossible, but I can deal, but at the same time, it's just. I did get in there once and made a salad for dinner and that was God, that was within the last, I guess, month. And that was, it's I felt as though I'd accomplished something by doing that. But that was it. And I have gotten my sister, who isn't a big kitchen person, cooking, but does take direction really well. So I've been remote controlling her, go do this and, so that's been alright. But again, it's like a lot of times I'll just look at, Door Dash or whatever, and Panera sounds good or let's order some soup or, whatever. Yeah.

Now a word about our sponsor, ABRIDGE.

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Smoke signals welcome 15:03

Health Hats: Are you open to people contacting you?

Mighty Casey: Yes. But managing expectations, I don't know, it's like the phone I will not, it's not that I won't answer the phone. But I don't always. But that's been true.

Health Hats: You have that nice message. 'I answer my messages at two, four and six' or whatever.

Mighty Casey: Mostly to manage expectations, but, yes, I'm open mostly to asynchronous communication. In other words, email, DM, texting, et cetera is fine. I do welcome phone calls from people that I actually already know, as opposed to just people who have heard about what's going on



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and maybe know me a little bit or, whatever. I'm fine with people who don't necessarily know me super well getting in touch, but again, that's more of an asynchronous choice, as opposed to turning up at my door. Although I will say that, various people have gotten in touch with me about stopping by, and I don't have a problem with that idea either again, as long as I know just popping up.

Health Hats: I was on the phone yesterday or no, the day before with Jan Oldenburg. And she told me her husband had dropped in and

Mighty Casey: So he had come because it was like an Amazon thing. My brother was coming and ordered this couch, pull out thing from La-Z-Boy. I ordered it to replace the futon. Futons are ridiculous. They're fine until you turn 50 and then your spine is no, but anyway, so I had a futon in here from the time I moved in here 16 years ago, but then, it's fuck the futon and let's get something a little bit more but it was like this to-ing and fro-ing with La-Z-Boy and whether or not it was going to arrive. And my brother was coming and I needed to make sure that I had something he could sleep on. So I ordered a roll away bed as like plan B and then that arrived. And then the La-Z-Boy thing was arriving. So, it was like we had too many things going on. So John, Jan's husband came over because I had to go to radiation and can't be at two places at once. He came over and accepted the delivery of the roll away bed or no, yeah accepted the delivery of the roll away bed. And then I had to send that away again, like a couple of days later after La-Z-Boy had brought in the goodie you a lot of them, so it was just a lots of to-ing and fro-ing

Self-advocacy towards...? 17:27

Health Hats: So let me ask you a question. You're an amazing advocate for other people. How is it going for yourself?

Mighty Casey: I do an okay job. I think of, standing up for myself. Right now it's not really knowable to know whether or not what's going on, what, what we're doing, the radiation in this, hormone, suppression experiment, the hormone suppression drug that I'm taking, like whether or not any of it's doing me any good at all. Because the only way to really tell if something's working is with scans and it's too early. The scans that revealed my problem are only, like a couple months old and you know what there needs to be, I think at least another say, 30 to 45 days of continuing to take this medication. I've only been on it for a little over a month. And because of my blood work being, some of this due to the fact that I'm not eating a lot and they're just, blood work has been a movable beast. Lot of my minerals, calcium, magnesium all of that. Most of my minerals are on the low end. And supplementation, we're working on that. And they have infused me with some stuff, like calcium and a couple of other things. I'm not getting infusions in the classic oncology sense. In other words, like chemo drugs, but I do go to the infusion center every couple of weeks for blood work. And depending on what the outcome of the blood work is, they may strap me into a chair and fill me with fluids or whatever. Trying to be better about eating. I'm feeling a little better than, I'm feeling a little bit more appetite than I had a month or so ago. Yeah. And things are starting to settle down a little bit, but it just it's been a ride.



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Back to drinking 19:24

Health Hats: Yeah. How about hydration?

Mighty Casey: It's like drinking water is my thing. Yeah. And you're still able to do that. And I have my water bottle with me. This is the one I carry in my backpack. It's no longer in the backpack. It's sitting next to my chair, but this way I can monitor, there's an amount ounces listed on here. So if I get through this four times in a day, then I've hydrated. Okay. It's difficult to know again, whether or not what we're doing is having any impact on the outcome what's going on inside my Corpus. So it's difficult to tell. And there's really no way of knowing now. I have not heard from my own team, whether or not they're gonna no start scans anytime soon. So my guess is sometime in late June or early July, they'll probably start thinking in terms of doing some scans to see if anything's happening. In the meanwhile my focus is going to be on trying to get some kind of clarity on whether or not I'm ever going to be able to get up and walk around again. And working with the spinal guy on whether or not, that's going to be like possible. I want to think it is, again, this is going to be up to the professionals and whether or not they think that, I'll be able to get up and move.

Waiting for palliative care 20:57

Health Hats: So the last time I talked to you, you had talked about palliative care coming,

Mighty Casey: Yeah. I have an intake appointment in a couple of weeks with palliative care. Let's see, hang on a sec. A week from Wednesday, I have an intake. Yeah, cause I, I guess the time of year plus, maybe who knows there could be a whole lot of cancer happening out there. I don't know. I only know what's happening with me. And yes, I have cancer, but I've got a palliative care yeah. Intake appointment on a week from Wednesday. And that's with somebody, a group that it's part of my overall oncology bunch and they come highly recommended. So yay. And palliative care, I think will also, and, my spinal guy also said, palliative care will be part of that. Absolutely. They may have some medication ideas that go beyond what I'm already doing. We'll see what happens and try to get everybody working in concert. And then I'm also, again, waiting on a thoracic MRI ordered from the spinal guy and we'll see what happens with that. There could be some metastatic process crap going on within my spine that is causing some of the, I don't know, let's wait and see. But we won't know until we see the pictures and I'm just really tired. I'm tired, I'm just, full on tired, but I'm also tired of not being able to move and tired of feeling nailed to the perch, but I have to hope that it's at least addressable. Yeah. And then so that's where I'm sitting in my head right now. It's know, find the problem you can solve and then go for that. Or find the problem you can attack whether or not it's curing metastatic cancer. Maybe there's a big eraser and maybe this eraser, that we're using, maybe it's working, I don't know. Or at least it's erasing it enough that, who knows, we'll see what happens, but yeah that's one of those things it's okay, I'm doing okay. What I can, in other words, I'm following my treatment plan. I'm doing, what's on the list. And we'll see where we end up. Yes. But in the meanwhile the things that are frustrating me and the things that are impacting my quality of life. Okay. Let's work on that. Yes. And that's the mobility issue, et cetera. I don't know if that really answered your question, but I'm I'm advocating for myself in ways that okay. What's the problem we can actually like address right now and let's go.



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Not alone, a big deal. 23:36

Health Hats: Yeah. Plenty that's a lot.

Mighty Casey: It's true. In the meme-speak of our times, welcome to the third millennium. Yes, it's a lot, whatever it can, any of it can be a lot and yes, I've got a lot going on right now. But again, it's not as though I'm in any way trying to minimize it, or push away the impact or importance of what it is I'm dealing with, but the fact is that I'm not alone in this. First of all, I'm not alone because I know a lot of people give a shit and are out there pulling for me, which makes a big difference. Trust me, I know what's there and it makes a big difference, but at the same time, as much as I would like to respond in the moment to everyone who is wishing me I can't always manage that. Just know that I know, and that it is hugely appreciated.

Not dead 24:38

Mighty Casey: One of the challenges has been trying to make appearances or at least pop up from time to time in a way that people know I'm not dead. But also that I'm not like just like wandering in sounding like some shadow of myself and then disappearing. It's like ten seconds isn't necessarily going to reassure anyone that I'm not dead. And so I'm trying not to do that, which is one of the reasons that I haven't done much since. I guess it's been a few weeks since I put anything up on my podcast channel.

Health Hats: Which is why we're doing this.

Mighty Casey: Why we're doing this. I do think that it probably isn't a bad idea that I have conversations with friends, from time to time being you, whomever cause there's certainly a number of people that I could have conversations with.

Present traumatic stress disorder (PTSD) 25:33

And I have had conversations with, and the most recent one, we did not record. But I did, mention it on Twitter, but my buddy Sally Crouse who is in a writer and health researcher in the UK who the last time she and I saw each other was in Edinburgh at Cochrane back in 2018, but she had a cancer adventure that was kicking off around that time. She wrote a really good piece about PTSD and cancer. That went up on the evidently Cochrane blog, sometime in the last year-ish. And that is really speaking to me a lot right now. And because, when it comes to PTSD, post-traumatic stress disorder, and cancer, there really is no post when it comes to to cancer because. Particularly if you're dealing with stage four, because it, there's no posts it's just there. Yeah. It is current. It's present.

Health Hats: P is present

Mighty Casey: P is present. There is no post. It's just, it's it's traumatic stress disorder, there's no P. And, unless you want to go for the present, present traumatic stress disorder, PTSD.



Let's do this again 26:38

Health Hats: Oh goodness. So my plan is I'm going to beam you a link to the Dropbox folder this is in, and then either you can do something with it, or if you want me to do something with it, send me your intro and outro, and I will cobble it together.

Mighty Casey: I probably will work up a new intro and outro for this stuff. Okay. Just, because, it's different and then I'll work on it over the next short period of time and put something up on my, and then you can certainly do whatever the hell you want. And you don't need, you don't need to worry about putting up, about editing it with my stuff, because I'll just send you the link to my Patreon and it, and then you can do your thing with it, whatever it is you want to do. Okay.

Health Hats: How about we do this again in a couple of weeks,

Mighty Casey: That works. That works.

Health Hats: Casey. I love you.

Mighty Casey: I love you too. And, it's it matters that, people, like I said are out there giving a crap about whether or not I'm still breathing, but it's I recognizing that within my ability to deal making some kind of an appearance every once in a while it's not the worst thing in the world. But again, I appreciate it and I want to make sure that I don't scare the crap out of anybody. And at that this point, I don't think I am. But it's, as they say, it's a lot right now and I'm trying to deal with it as best I can. It's a daily struggle, but so far I'm still here. So great.

Health Hats: Talk to you soon. All right, my love, take care. Bye bye.

Reflection 28:21

So much packed in this tube, like a sausage casing. One morsel in front of the other. Not so hilarious. Living alone with mobility issues. It's here, there, next door. Frightening at best. How to help? I live in Boston, not Baltimore. What to do? Recording tape for Casey's podcast. Then repurpose it for my selfish self. What can you do for your next door neighbor? Probably anything would be welcome. Don't worry about missteps. Just do it and take the risk. What's a misstep inside caring? Oh goodness. Take care. Until next time.



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