Contents

Proem	1
Enough control to call 911 on me 02:23	
Mobility, pain, the Outer Banks, and Rockettes 06:17	2
Stay put, avoid the stairs, recognize privilege 08:58	3
Spirits, sorting out home health 11:40	4
Alive, eating, cooking 14:05	4
Working for a Yankee dollar 18:07	5
Receiving end of hospitalists. Coordination of care still on me. 20:37	6
Connection 23:39	7
Reflection 25:27	8

Proem

Our friend and inspiration, Casey Quinlan, returns from five days in the hospital. Casey authors and produces a podcast, <u>Healthcare Hilarious</u>. I sponsor <u>Healthcare is Hilarious</u>. Since this bit of fun with Stage IV metastatic cancer, Casey lacks the energy to maintain her weekly delivery schedule, so I'm recording our exchanges. Casey can use them to keep her fans and followers up to date. Listen to the raw, unedited version #MetsParty goes to the hospital <u>here</u>.

Why do I cross-post this dialogue? I never record conversations with people in the throes of their health challenges on this podcast. Why not take the opportunity when it appears? Who has that kind of energy when they're down? Remember those 2Cs I've spoken about in the past? The 3Ts and 2Cs of best health (trust, time, talk, control, and connection). When you feel like crap, control and connection take a hit. By their very nature, hospitals and feeling like crap eat control and connection for lunch.

Let's check in with Casey.

Enough control to call 911 on me 02:23

Health Hats: So, you're home. Why'd you go in?

Casey Quinlan: I had not grasped this because you onboard a lot of information when you end up in a situation like, let's say, a stage four cancer thing. There's lots of information aimed at your head. I do like to think that I retain a lot of it. But it doesn't all stick. And I don't know that I've gotten the memo that somewhere around 25% of the people who end up on the drug that I'm on, a Pfizer drug specific to hormone-positive breast cancer, particularly recurrence at a later stage. They start you with a dosage of a hundred milligrams, and it looks like that dosage is too high for me. About 25%, I think, or at least this is the information that I've grokked so far, about 25% of us who end up on this medication end up with



some kind of GI gastrointestinal impact. And it can go in either direction and either plug you up or not. I was dehydrated. I called 911. No one had to do that for me. I did it for myself because I knew that I was in trouble. This wasn't getting any better. It was getting worse. I did not realize that it would be five days, four nights, or whatever it was. But here comes the EMS crew and out the door, and I was there. That's how long I was there. And before my landing in the hospital, we've been chasing. When I say we, like everybody, had been chasing the fact that my blood pressure was really low. To the degree that it's, is she still alive? And also chasing blood mineral levels that were way out of whack. I was pretty sure in the parts of my brain that were still online and working on the cognitive side, I was pretty sure that I was going to spend at least a night in the hospital, particularly around calcium and magnesium and yeah, just, everything was completely jacked. When I had gone into the oncology center for infusions, it had nothing to do with chemo. I'm, I'm not on a chemo, classic chemo regimen, but I would go in and get hydrated and also get a mineral infusion. So, the bottom line is they're changing the dosage on the medication I'm on the cancer medication from a hundred milligrams to 75. When that arrives, I'll start retaking it. For now, I'm not

Health Hats: You're not on it at all?

Casey Quinlan: I'm not on it, but that's the cadence on this drug - three weeks. You'd take it for three weeks and then seven days off and then three weeks on and then seven days off like old school birth control bills anyway. Or maybe birth control pills are still that way. I don't know. I'm old. It's been a minute since I had to worry about pregnancy risk. Anyway. But I am old enough to remember before Eisenstadt v Baird. So, I have stories, but my next appointment, conversation with my oncologist is Tuesday, a virtual visit, and we'll discuss the dosage.

Health Hats: Casey knew she was out of whack and called 911. Typically, the ABCs (airway, breathing, circulation), pain and disorientation cause malfunction. Ideally, hospitalization provides a bridge to returning function. For Casey the malfunctions were dehydration (circulation) and pain. I wonder how much of the first few hours she remembers, before she was rehydrated with IV fluids?

Mobility, pain, the Outer Banks, and Rockettes 06:17

Health Hats: You were also having a lot of pain, right?

Casey Quinlan: Yeah. Mobility has been a never-ending unicorn since I started dealing with what seemed to be a return of spinal problems that I've had for low back sciatica. But I was chasing that since August of last year, when it seemed as though I had tweaked myself somehow on my birthday, as I went over a dune down on the Outer Banks because it was my birthday and the beach, and let's play. So, I did. And the next day, I woke up and just felt tweaky and in my lower back and right hip and so from August of last year until a lumbar. MRI revealed metastatic cancer in my spine. It was seven months of chasing this as a spine issue. But I have lots of warning signs there because there's plenty of evidence, people could go and listen to me, tell that story, but I, it's no matter what I did, whether it was swimming or physical therapy or whatever. All the things that had previously helped me recover from back problems made it worse. And it's this makes no sense. As a result, we discovered that it doesn't make any sense



because that's not what's going on. What's going on is you have metastatic cancer. Oh, that everything much clearer, but now we're chasing a whole other problem.

Health Hats: So, when you went to the hospital, was your pain managed at home or not?

Casey Quinlan: It wasn't not managed at all. But what I was taking, I had been on five milligrams of Oxy, just, tablet, Oxy, every, as needed. Then the palliative care bumped that up to 10 milligrams, every three hours and just again, a pill, but in the hospital the last couple of days I was there, they switched me to a 10 milligram, 12 hours extended-release. that turns out to be there at least so far. That's been because it, it's I can now actually get up and walk with my walker. I can take a couple of steps before, but it was not pretty. And now it's. Still, it's not like I'm, doing a Rockettes kick line. Do not mistake me. Getting back in the pool is something that seems possible now. Until a couple of weeks ago, that was not feeling like it was on the list of shit Casey can end up doing.

Stay put, avoid the stairs, recognize privilege 08:58

Health Hats: I talked to you briefly when you just got home. You were committed to not leaving the house for a few days.

Casey Quinlan: A week, two weeks, two weeks. Okay. Okay. That's working. I'm going to be 100% that bitch. And it's just nope; I am not leaving the house. Until after the 10th of July I will entertain the idea that I might go out, go down the stairs, get into a car, and go somewhere. But until then, baby, don't play. I know that this works, or can work, does work because of the home health lash-up available to me.

I will now take a short break to mention that I recognize my privilege; I deeply recognize my privilege as an old person who elected to go with original Medicare, not that Medicare Advantage managed-care mess, but original Medicare. I had a broker work with me to pick the right plan for me, and it just, but knowing all of that all, yeah, I didn't have to pay the broker, the insurer, the people who sell the supplements or whatever, pay the broker. Most elders, people who were aging into Medicare, don't know that this kind of stuff is available to them as services, help guidance consulting, pick one. But because I'm me, I knew this. So anyway, I have really good Medicare. I'll put it that way and not that it pays for every last little thing. It will not pay all of the ambulance that brought me home on Saturday, but again, grateful for privilege. I am in a position to pay that it'll probably be 600 to a thousand bucks, but it's fine. I can do that. And I am grateful that I'm in the position to do that because that way when I got home, I didn't have to navigate the stairs. They brought me into the apartment. They didn't have to carry me to my bed. They got me in the door. And then once I got in the door, I'm here. I got my walker.

And don't get between me and the shower. That would have been a life-threatening move if you got between the door and the shower that day. Because I set a land speed record showering. Like a regular shower schedule is important to me. I like bathing. It's totally a thing here.

Health Hats: You know Casey's feeling better because she can appreciate her privilege.



Spirits, sorting out home health 11:40

Health Hats: How are your spirits?

Casey Quinlan: Compared to a week and a half ago, I feel like me again. I'm not at a hundred percent. I'm at about probably 75%, but yeah, but somewhere around there. And yesterday we had home health here. I'll wrap up, do not leave the house for two weeks, every medical bunch wants me to get blood work or have a physical exam or whatever, send home health if they can do that. And the care transitions bunch of the hospital contacted me, one of the nurses, or the nurse practitioner and said, we really want you to see your primary now that you're out of the hospital. And I said, since I'm not leaving the house, how about we figure that one out? And she said, how about I send Dispatch Health? Which is the physician assistant and bunch that comes in to do medical procedures. When I say medical procedures, phlebotomy, they also do physical exams, et cetera. So, she said I can send Dispatch Health. And I said they know where I am. They've been here before. And that, that got sorted out. And then, on the flip side, I still like being able to be helpful and do what I do as the work that we both do is that when my palliative care team called me. It was when Dispatch Health was here doing the physical exam. And I said, hey, that Dispatch Health is here doing my post-discharge physical exam to make sure I'm all good. And the palliative care nurse was like, they do that. I'm like, yeah. She said that's really useful information. Put it in the book, put it in the book with the logistics of the stuff for your patients, because this is invaluable. But anyway, it's like knowing that these services are available. And again, I live in an area I'm not out in the middle of fricking nowhere. I live on the bridge of urban, to suburban and I'm surrounded, the big academic medical center here, hospitals out, hot and cold running hospitals. We've got doctors out the wazoo here. It's not Boston in New York, but it's damn close. If you're going to get sick, this ain't a bad place to be.

Health Hats: Because there's a variety of services available to you?

Casey Quinlan: Yeah. In some ways there can be competing. There's not just one place that does it. And you can figure out the one that you liked the most.

Alive, eating, cooking 14:05

Health Hats: I spoke to you briefly, like one word when you were in the hospital, and now you seem more alive.

Casey Quinlan: More me. Yeah.

Health Hats: You have some energy.

Casey Quinlan: By the way, as of today, pot is legal in this state. Oh yeah. That's in the mix. Okay. I had bought a vape that does both essence and oil and flour. I hadn't been using it, but now recognizing that one of the things that are going to be on my task list is side effects management, not just me, but side effects management, understanding that appetite enhancement is probably going to be, on that list of things I need to do for myself. Weed is a very good munchie trigger.



Health Hats: And you've lost a bunch of weight.

Casey Quinlan: Yeah. I've probably lost somewhere between 40 and 50 pounds. And which, on, not as though I, not as though losing weight is a bad thing if you are a large person, I wasn't huge, it certainly no one would ever describe me as skinny. It's like at this point, I want to regain strength but not necessarily put the weight back on.

Health Hats: What kind of exercise, routine do you have when you say that?

Casey Quinlan: What I'm doing is getting up and walking, using my walker. In addition to having home health, Dispatch Health, whatever, I also have physical therapy and occupational therapy. PT and OT coming to it helped me with PT with exercising and moving. OT just with, okay, how are things appliance wise, et cetera, and all of that are covered, they can help me. When the OT human was here yesterday, one of the things that we did was we went in the kitchen. I ended up making dinner last night for the first time.

Health Hats: I saw your picture on Twitter, probably like a month or more, and I see asparagus on that plate?

Casey Quinlan: No, actually, it wasn't asparagus. It was peas. But what I did was it was penne, a chicken breast, some Italian salami and peas with parmesan and a little olive oil and garlic. And there's enough for leftovers for dinner tonight. I will add some really good pesto, jarred pesto from Italy to what's already there. So, I don't have to go and cook the whole thing again. It's more like, but I will admit that I may have been more enthusiastic about my capabilities yesterday, as far as being able to get up and move around and whatever. I may have overdone a tiny bit because my low back is a little sore today, and that's, but not, it's not oh my God, I hurt myself. It's more oh, okay. I was so excited about the idea that I could move around, but I may move 5% more than I really ought to. Yeah. But that's fine.

Health Hats: Coming out of the hospital, it's hard to re-equilibrate capability, and you're likely to overshoot the mark.

Casey Quinlan: Yeah. Know what your capacity is. I certainly didn't do myself injury.

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Working for a Yankee dollar 18:07

Yesterday I also spent a good bit of time at the desk. One of the things that I do for an actual Yankee dollar is package or produce; depending on what the ask is, I package podcasts for Wiley, the publisher,



and medical societies. The two that I work on right now, one is for the American College of Emergency Physicians. And I just package that, mostly I do a transcript and get it the other front end. I think you don't hear me on that. You don't hear my voice, and then there's the otolaryngology. The International Forum of Allergy and Myology and their podcasts scope it out that's been going for over a decade now, and I produced that and do the voiceover at the front backend and billboards.

Health Hats: And do the show notes and stuff like that?

Casey Quinlan: I don't want, no, I just turned that I just audio file no show notes for that. I've got a stack of four. Three now because I finished one yesterday, but I've just got a stack of, a total of four for the emergency physician bunch. And one of the reasons I love doing this stuff like this is that I learn things and find out what's going on in, on the doctor's side of the stethoscope, which got started, like for almost a decade. Close to a decade. I did the hospital medicine stuff for the Society of Hospital Medicine. So, the hospitalists, yeah, the hospitalists, when Bob Wachter and S H M took that back inhouse. In other words, Wiley didn't have the contract after I want to say. Four years ago, or so, but anyway, I did it for many years podcasts, couple podcasts, and month, and started doing videos. But I learned a massive amount, just listening to, reading about coming up with the topics, reaching out to the experts, interviewing them, and then packaging it together. This is how I know shit. And being a journalist, it's coming up with I don't know that much, but I'm going to read up on it and then I'll to come up, I'll come up with five questions that seem intelligent to me, and then we'll talk, and I will share it.

Health Hats: I appreciate that Casey uses podcasting as an opportunity to learn. I use podcasting as a chance to listen, think, and craft connections (connection between people and ideas).

Receiving end of hospitalists. Coordination of care still on me. 20:37

Health Hats: That's great. How was it on the receiving end of hospitalists when you were at the hospital?

Casey Quinlan: I can't say that I got hospitalists'ed to a fare thee well, by any stretch. One hospitalist, a woman, came and was there a few times, and she did what she needed to do. And I think she was the one that put me on the extended-release pain med. So that was thumbs up to the hospital crew doing that. And in concert with the palliative care and the ONC team, because my palliative care and my oncology team also came to see me now.

Health Hats: Oh, they did. So how did you, what was your view of the coordination of care?

Casey Quinlan: It was on me, but none of that was a surprise. It's like knowing that the person in the bed or the person who's in the room with the person in the bed needs to be the care coordinator or participate in care coordination. It's you just gotta know that going in. And it's not as though there will be no care coordination if you don't do that. The yawning gaps happen when the people on the receiving end aren't paying as much attention as the people on the dispensing end.



Health Hats: It always seemed to me like as a nurse or whatever, is that It was so much to ask you don't get in the hospital unless you're pretty messed up. And it's really hard to focus because you're just, gazing at your navel because you're in misery.

Casey Quinlan: I will say that the first couple of days I was, I just was, again, I'm just, on the receiving end, I was just on the receiving end, not as though I wasn't, like listening or paying attention or able to onboard what they were telling me saying to me, et cetera. Let's say Monday night and Tuesday night into Wednesday, I was, just a lump. But as of Wednesday, I was still on a liquid diet chicken broth, et cetera. I think it was Wednesday dinner; they put me back on solid food, and it was realizing that food was a good thing was nice. Cause I hadn't had an appetite for probably a couple of months, and when the food showed up, it not only was it a tray of food, but it smelled good. I couldn't eat the whole thing by any stretch, but what I ate, and it was, like there was rice and protein and like some perfect seasonings. It was a little spicy, not a lot, but just a little kick to it. There were some nice black beans like they know me my palate likes. Then after that, food arrived, breakfast, lunch, and dinner, and I'd have a little bit of each tray. And it was like, oh, okay, great. So, food is back on pleasurable things.

Connection 23:39

Health Hats: Did you have visitors?

Casey Quinlan: Yeah. Jan Oldenburg who lives locally and has been a friend and colleague for over a decade now. She and John, her husband, moved down here in 2015, but anyway, they're local, and she came and saw me a couple of times in the hospital, and my sister's here keeping the home fires burning. Then starting Thursday morning, I feel trapped here. I gotta get outta here, but how do I do that? And as it turned out, Saturday was the day that I was going to go over the wall. So, I did,

Health Hats: Lovely. I'm glad. Looking and sounding like yourself.

Casey Quinlan: So far so good.

Health Hats: I know that there are many people eager for news.

Casey Quinlan: People who actually know me, like you who are in my phone are welcome to call me. But again, whether or not I answered the phone is up to did I see the phone ringing and am I in a position to be able to answer. It's fine. I welcome calls.

Health Hats: All right, darlin. It's good to see you. It's good to talk to you.

Casey Quinlan: Good to be seen.

Health Hats: Yes. Take care of yourself.

Casey Quinlan: I will. I love you, man.

Health Hats: I love you too. Bye.



Reflection 25:27

Stage four mets, rehydrated, eating, and working. I'd say a successful hospitalization. Casey, thanks for your view from the inside looking out.

